The effectiveness of a caregiver-directed intervention promoting development in HIV-positive children on caregivers' self-efficacy: A randomised controlled trial

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Declaration

I, Jessica Ferguson, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise). I have used the American Psychological association 6th Edition referencing system. I declare that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abstract

Background

Caregiver self-efficacy (CSE) supports the capabilities of caregivers to engage in parenting activities including stimulating development in their children. Human immunodeficiency virus (HIV) remains a prevalent concern in South Africa, even with the use of antiretroviral treatment. Children with HIV are compromised in their health and development which adds to the general stress of families rearing HIV-positive children. Stress has a negative effect on CSE. However, studies indicate that CSE can be improved through parent-mediated intervention. Caregivers' engagement in the intervention may grow their skills to promote development in their HIV-positive children. This may have a positive influence on CSE. Occupational therapists working in governmental paediatric HIV clinics developed a play-informed, caregiver-implemented, home-based intervention (PICIHBI) for HIV affected families to be implemented. This study evaluates the effectiveness of PICIHBI on CSE.

Aim

The aim of the study is to determine if the CSE levels in a group of caregivers of HIV-positive children aged 6 months to 8 years 0 months on ART, after receiving play-informed caregiver-implemented home-based intervention (PICIHBI) are not inferior to CSE levels in an equivalent group of caregivers with children receiving conventional one-on-one occupational therapy.

Methods

The study applied a pragmatic, randomised control trial with caregiver-child dyads attending the antiretroviral clinic at Groote Schuur Hospital, Cape Town. The control group received conventional child-directed occupational therapy on an individual basis and the experimental group received caregiver-directed, PICIHBI in a group format. The Parenting Self-Efficacy Measure (P-SEMI), Parenting Sense of Competency (PSOC) scale, and the General Self-Efficacy Scale (GSE) measured self-efficacy at baseline, half way and at the end of the yearlong, monthly interventions.

Results

Sixty-four caregiver-child dyads were recruited and assessed at baseline. Thirty-nine dyads were retained in the study, completing the measures at all three test points. Results revealed that

baseline CSE was high for both groups. There was a significant change ($p < .001$) in the P-SEMI total scale in both groups from baseline to mid-test and mid-test to post-test. In both groups the CSE scores decreased from baseline to mid-test and then increased from mid-test to post-test. There was not a significant difference in CSE results between baseline and post-test on the P-SEMI total scale for either groups. There were no significant differences between test points for the other scales and subscales for both groups.

Conclusion

The results suggest that PICIHBI has a non-inferior effect on CSE to that of conventional occupational therapy. This suggests that PICIHBI is comparable to conventional occupational therapy and could be implemented as an alternative intervention without comprising the effects on CSE. Employing PICIHBI as an alternative intervention could provide a number of benefits including the development of caregiver skills, a larger reach within the population, and contextually driven intervention that is embedded in children's home environments. Various influencing factors are proposed to explain the patterns of CSE demonstrated in the groups. Neither group showed a significant increase in CSE from baseline to post-test and thus further investigation and intervention development is required to specifically demonstrate enhanced CSE in this context. Intervention attendance for both groups was poor. This is the first investigation on the effects of PICIHBI on CSE which can inform further research to develop best occupational therapy practice in the vast population of HIV affected families.

Trial registered with South African Department of Health (2013 RP 185).

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Abbreviations, acronyms and definitions

ART	Antiretroviral therapy
ARV	Antiretroviral
CSE	Caregiver self-efficacy
DF	Degrees of freedom
GMDS-R & ER	Griffiths Mental Developmental Scales – Revised and Extended Revised
GSE	General Self-Efficacy scale
HIV	Human Immunodeficiency Virus
GSH	Groote Schuur Hospital
Kidzpositive	The Kidzpositive Family Fund
M	Mean
Mdn	Median
OT	Occupational Therapy/Occupational Therapist
PICIHBI	Play-informed caregiver-implemented home-based intervention
P-SEMI	Parenting Self-Efficacy Measuring Instrument
PSOC	The Parent Sense of Competence Scale
SD	Standard deviation
SES	Socioeconomic status
UCT	University of Cape Town

Definition of terms

Caregiver: A person who has accepted primary responsibility to regularly look after a child and conducts various parenting tasks. A caregiver can include a biological parent, family member or guardian. Both male and female caregivers are included in this definition.

Caregiver-directed intervention: Intervention that is conducted with the caregiver as the main recipient of the intervention from the therapist. Caregiver-directed intervention is administered to the caregiver, who further mediates intervention with their child.

Caregiver-implemented: The action of the caregiver directly applying learning and carrying out activities with his/her child.

Caregiver self-efficacy (CSE): Commonly referred to as parental self-efficacy, caregiver self-efficacy is the caregiver's "beliefs in his or her ability to influence the child and his or her environment to foster the child's development and success" (Ardelt & Eccles, 2001, p.945).

Development: An individual's process of maturation of function and skill (Law, Missiuna, Pollock, & Stewart, 2005).

Home-based: At home or the caregiver's own time and space, outside of the clinic.

Learning: This study refers to learning as the advancement of foundational skills that contribute towards academic progress, including practical reasoning, visual motor integration, pre-numeracy and pre-literacy skills.

Play: A primary childhood occupation through which a child engages with their environment for enjoyment, social engagement and/or to express themselves (Parham, 2008).

Play-informed: Intervention framed with an understanding and value of play within the child's context.

1 Caregiver Self-efficacy

1.1 Introduction

A caregiver holds beliefs about their capability to perform child-rearing tasks. Caregiver self-efficacy (CSE) can be defined as a caregiver's "beliefs in his or her ability to influence the child and his or her environment to foster the child's development and success" (Ardelt & Eccles, 2001, p.945). CSE has a reciprocal relationship with caregiver skills and competence (Bandura, 1997). CSE is an integral constituent in fostering caregiver competence and allows for caregivers to support their children's development (Bandura, 1995; Dorsey, Klein, & Forehand, 1999; Teti & Gelfand, 1991). At the same time, competence and development of caregiver skills can also influence CSE (Hess, Teti, & Hussey-Gardner, 2004; Wittkowski, Dowling, & Smith, 2016). Caregiver competence can be greatly encumbered by the stressors in the child-rearing role for any caregiver, regardless of caregiver characteristics or child health (Bandura, 1995). Moreover, caregivers of children who are HIV-positive have been found to display clinically significant levels of clinical stress (Chalfin, Grus, & Tomaszeski, 2002; Potterton, Stewart, & Cooper, 2007). In South Africa, caregivers and children affected by HIV also have a greater probability of being economically disadvantaged and are often subjected to limitations in access to support and health care services (Potterton et al., 2007; Webb-Robins & Wilson, 2008). The additional demands of medical conditions, such as HIV, and contextual strains on the occupation of caregiving can lead to low CSE (Dorsey, Klein, & Forehand, 1999; Holland et al., 2011). Low CSE negatively impacts on the caregiver's own wellness and their ability to engage in caregiver-child interactions which promote child development and consequently the child's future trajectory (Okeke, 2016; Peacock-Chambers, Martin, Necastro, Cabral, & Bair-Merritt, 2017). In South Africa, this is of particular concern given the high number of HIV-positive children and limitations in support from health care services (UNAIDS, 2017).

Occupational therapy is a profession that can empower caregivers with skills to optimise child outcomes and influence self-efficacy (Gage & Polatajko, 1994). Caregiver-directed interventions have been developed to equip caregivers with skills and behaviours, improving their sense of competence within the parenting role which may modify their self-efficacy beliefs (Wittkowski et al., 2016). However, group-based intervention targeting self-efficacy in caregivers of HIV-positive children to

promote development in children within a South African governmental clinic setting is limited in research.

1.2 Problem statement

It is well known that HIV is a predominant concern in South Africa. There has been a reduction in new HIV infections among children through prevention of mother to child transmission initiatives (UNAIDS, 2014). However, perinatal HIV statistics are still high with 320 000 children aged 0-14 years infected in South Africa (UNAIDS, 2017). Caregivers face daily challenges when rearing healthy children, however, those with HIV infected children have to deal with additional demands. These include coping with the psychological stress of raising an HIV-positive child; continual dealings with health providers; medication management; and societal stigma (Demmer, 2011). Furthermore, many studies have revealed that HIV has an adverse effect on child development thus placing greater pressure on the caregiver to support their child's development (Burns, Hernandez-Reif, & Jessee, 2008; Foster et al., 2006; Potterton et al., 2009). Caregivers who raise HIV-positive children often experience many psychosocial challenges and often struggle to cope with the role of caregiver (Chalfin et al., 2002; Demmer, 2011; Richter et al., 2009). A South African study conducted in Soweto revealed that caregivers of HIV-positive children endure extremely high levels of caregiving stress to the extent that they require referral for further clinical examination (Potterton et al., 2007). Furthermore, caregivers could be experiencing stigma as an HIV affected family. It has been found that HIV stigma mediates the relationships between general self-efficacy (Li et al., 2011). Biological mothers of children with HIV transmitted via vertical transmission are also fighting their own HIV symptoms and trying to manage their own health and well-being (Demmer, 2011). Mothers (and grandmothers) also tend to suppress their own needs and put the child's needs first (DeMarco, Lynch, & Board, 2002). Mothers who undergo persistent physical and emotional exhaustion may struggle to cope with the associated stress, affecting their sense of competence to manage the caregiving role and consequently acquire lower levels of CSE (Dunning & Giallo, 2012). Results of a study conducted by Dorsey, Klein and Forehand (1999) revealed that HIV-infected mothers have significantly lower levels of CSE compared to uninfected mothers. This suggests that CSE is a variable in HIV-affected caregivers that is influenced by the circumstances of the HIV diagnosis and it is worth investigating intervention impact on CSE in these caregivers.

HIV infections are particularly rampant among South African families living in low income areas. Caregivers and children with HIV are thus likely to experience additional adversities associated with poverty. Poverty suggests a high unemployment rate amongst caregivers, financial stress and emotional depression (Lachman, Cluver, Boyes, Kuo, & Casale, 2014; Richter et al., 2009). Depressive symptoms have been shown to have a significant inverse relationship to levels of CSE (Bandura, 1995; Holland et al., 2011; Jones & Prinz, 2005; O'Neil, Wilson, Shaw, & Dishion, 2009; Sevigny & Loutzenhiser, 2009). In these impoverished circumstances, food security, gaining an income and material needs can take preference for a caregiver over meeting their own emotional needs (DeMarco et al., 2002). These burdens of needing to meet basic material needs can overshadow the need for time for grieving and dealing with diagnosis, and seeking support (Demmer, 2011). Prioritizing these basic needs also proposes that, for caregivers, spending time with their children to promote development may become a lower priority in this context. In addition, families in poverty may have limited resources for caregiving and stimulating their children thus leaving caregivers feeling ill-equipped to carry out these activities (Demmer, 2011). Primary caregivers, who are biological parents, often struggle with guilt in relation to the perinatal transmission of HIV and find it difficult to accept their children and status. This early guilt in the caregiving role can also influence the way caregivers feel about themselves and their competency in their caregiving role and thus may potentially influence levels of CSE (Demmer, 2011). Many caregivers in this context have also received limited opportunities for education which is a determinant that influences CSE (their perception of their ability to execute tasks successfully or access the help and resources they need) (Bandura, 1995). When a family is living under deprived circumstances, there is a paucity of external support. Consequently, there is a greater need for these caregivers to draw on their inner strengths for support in times of stress (Bandura, 1995). Thus, caregivers in these circumstances may capitalise in their belief that they are able to influence the direction of their children's lives more than a family with ample resources and social supports (Bandura, 1995).

With the heavy load placed on caregivers raising HIV-positive children, particularly those facing poverty, it would be beneficial for South African governmental HIV clinic services to design interventions to develop caregiving skills and self-efficacy. However, HIV clinics are burdened with high caseloads, limited resources and personnel shortages across the interdisciplinary health team. Typically, HIV clinic services primarily provide biomedical treatment of HIV and associated conditions to the child. Thus, the capacity for other forms of intervention that address child development, the

role of caregiving and related caregiver skills, is limited. The few clinics that have occupational therapists to address these needs typically provide conventional one-on-one services. Individual occupational therapy services are of benefit, however, with the large population in need and time required to implement strategies with individuals, the reach of these services is limited. In addition, the conventional model of service delivery typically involves the therapist mostly working directly with the child on child outcomes. This model can miss opportunities for the caregiver to actively develop their caregiving role and skills, and, limits child intervention to the clinic setting by relying on the therapist.

1.3 Rationale

Caregivers caring for children with HIV in South Africa are typically struggling with a variety of physical and psychosocial issues as mentioned above, that affect their health, well-being and performance in their caregiving roles. These difficulties can lead to a low level of CSE resulting in caregivers who struggle to cope and feel ill-equipped to take on a caregiving role with an HIV-positive child.

Occupational therapy is a profession that aims to equip and empower individuals and groups to be independent and successful in their life roles and occupations. Trombly (1993) mentions that "the overall goal of occupational therapy is to enable the client to gain a sense of efficacy" (p. 254). Occupational therapy looks holistically at facilitating what is needed for an individual or group to be able to feel satisfied and efficacious in their daily occupations. Occupational therapists are trained in a vast range of techniques and skills, and can employ appropriate techniques to achieve goals from analysing the specific requirements of the client and context. Among these techniques and skills are psychosocial and cognitive techniques, group work skills, experiential learning, modelling techniques, and skill development which occupational therapists draw on to provide interventions that enhance self-efficacy. Given the problems outlined above that could infringe on child development, caregivers may feel urged to stimulate their child but not feel they know how to do even the basic activities (Bloomfield et al., 2005). An undergraduate study was conducted with the same population of caregivers of HIV-positive children attending the Groote Schuur HIV paediatric clinic, as well as 3 other governmental clinics, investigating caregivers' perceptions and knowledge of child play (Ayliffe, Croney, Van der Veen, Wishart, & Ramugondo, 2013). The study results indicated

that, although child engagement in play was perceived to be valued, caregiver knowledge about play was limited (Ayliffe et al., 2013). This suggests that caregivers would appreciate play development but would be restricted in their knowledge and skill to provide appropriate play opportunities for progress. The results from Ayliffe et al.'s (2013) study further informed the development of a play-informed approach to intervention in addition to addressing child development and learning used in this study (see Intervention for further details on the intervention). Occupational therapy can create an opportunity for caregivers to problem solve and actively acquire knowledge and skills that will promote child development, learning and play. Consequently, this process could enhance levels of self-efficacy in the occupational performance of caregiving. Thus, occupational therapy can address the need for caregivers rearing HIV-positive children to be supported and skilled in a way that enhances CSE which could encourage further engagement in the process to develop caregiver skills. OT is well positioned to improve levels of CSE through equipping of skills, experiential learning and using therapeutic techniques that encourage caregivers to believe in their ability to promote child development, learning and play.

The Kidzpositve Family Fund (Kidzpositive), a non-profit organisation, was established in response to the additional support needed for children and families affected by HIV that governmental health services did not have the capacity to provide. An initiative of Kidzpositive was employing occupational therapists to address the developmental concerns of HIV-positive children. These occupational therapists (of which the researcher was one) found that treating children directly did not have a sustained impact on their development, particularly as clinic appointments were 1 to 3 months apart. Furthermore, seeing children individually took substantial time in the clinic day and the therapists would not be able to see all the children attending the clinic. Thus, it was recognized that a group-based intervention directed at caregivers could be a more successful way to provide effective, affordable and sustainable intervention to the large population of caregivers in need in the context. This led to the development of a play-informed caregiver-implemented home-based intervention (PICIHBI). PICHIBI is a monthly group-based intervention that takes place at HIV clinics with the goal to equip caregivers with skills to promote development, learning, and play that will carry over into their home environment. The details of the development and implementation of this intervention is outlined in chapter 3.

Studies have shown that general caregiver-directed programmes can positively modify CSE in caregivers with developmental or conduct concerns (Bloomfield & Kendall, 2007, 2012; Breitenstein et al., 2012; Gardner, Burton, & Klimes, 2006; Mouton & Roskam, 2015; Wittkowski et al., 2016). However, no published literature was found exploring caregiver-directed intervention influencing CSE in caregivers of HIV-positive children in the South African context. This study aims to explore the effectiveness of PICIHBI on CSE in comparison to conventional occupational therapy focussing on individual child-specific outcomes. Data from this study will assist to inform best practice in occupational therapy with HIV affected families in this challenging context.

1.4 Parallel studies

This study, along with three other parallel studies, are nested under one larger study (HREC: 560/2013) with Ramugondo as the principle investigator. Appendix A illustrates the outline of the parallel studies with the study title, population, and measuring instruments used. The larger study will explore the effectiveness of PICIHBI on the participation outcomes for HIV-positive children in learning, development and play compared with standard one-on-one OT intervention. The purpose of the larger study is to inform best OT practice for HIV-positive children to impact learning, development and play outcomes specifically in impoverished contexts where stigma and poor literacy levels prevail. This study forms a component within Ramugondo's study and was conducted in conjunction with the other three nested studies that ran concurrently. The studies drew from the same caregiver-child population attending the Groote Schuur HIV out-patient clinic. The studies all investigated the effectiveness of PICIHBI in comparison to conventional OT intervention. The other studies focused on the child outcomes of child development, learning and playfulness whereas this study has a primary focus on caregiver outcomes, namely CSE. Decisions around assessment and intervention procedures considered all the studies as to ensure that the process was viable and convenient for the participants to engage in all the studies.

This study addressed the following research question:

1.5 Research Question

Are CSE levels in a group caregivers of HIV-positive children on ART, after receiving play-informed caregiver-implemented home-based intervention (PICIHBI) comparable to CSE levels in an equivalent group of caregivers with children receiving conventional one-on-one occupational therapy?

1.6 Purpose

The study will document the effectiveness of a play-informed caregiver implemented home-based intervention (PICIHBI) on CSE for caregivers of HIV-positive children, by determining that the intervention is comparable to the current one-on-one intervention received in the public setting. The information generated in this study will guide which type of occupational therapy intervention will be most effective in enhancing CSE to promote child development in caregivers of HIV-positive children living in South Africa.

1.7 Significance

The need for supporting development and learning of young South African children has been recognized as a priority by South African government (Department of Education, 2012). The vision of the government can be seen in the South African National Curriculum Framework (NCF) for children from before birth to the age of four, which states "working with and for all children in the early years in a respectful way to provide them with quality experiences and equality of opportunities to achieve their full potential," (Department of Education, 2012 p.12). The NCF document highlights numerous key features that need to be implemented. One of these features covers family inclusion. The NCF recognizes that families need to be included into early childhood development programmes as they are the crucial educators of their children (Department of Education, 2012). Children with disabilities, including HIV/AIDS and children living in poverty, are also acknowledged to have limitations in learning and require special educational and care needs (Department of Education, 2012).

This research has significance in line with governmental objectives as it involves a trial of an innovative early childhood development programme aimed at supporting caregivers, facilitated by occupational therapists. This study's experimental intervention is also targeted at children with barriers to learning i.e. HIV-positive children (and their caregivers) in low socioeconomic areas. This study is the initial step to evaluate whether such a programme may be effective and feasible to roll out to more sites for further research. Research across multiple sites with a larger sample size could

determine generalizability of impact and inform decisions for implementation across governmental clinic sites in South Africa.

1.8 Conclusion

In conclusion, caregivers face many challenges when raising an HIV-positive child. These relate to the child's health and development as well as contextual challenges as a consequence of living in low income areas including, financial strain, survival for basic needs, limited resources and support, and stigma associated with HIV. With these challenges, a caregiver's sense of competency and efficacy could be affected. Bandura's (1995) notion of increasing self-efficacy suggests that it could cause caregivers to act differently and make different choices. Changing CSE levels could therefore be helpful in overcoming parenting challenges. Exploring effectiveness of PICIHBI could help inform OT practice to best support these caregivers.

2 Further literature review informing the study

2.1 Introduction to literature review[1]

This chapter describes literature, in addition to the literature included in chapter 1, that informed the study. The concepts of self-efficacy and CSE as well as the impact of CSE on the caregiver are explored. Research studies that have investigated interventions that have influenced caregiver self-efficacy and child outcomes are summarized. This chapter also further expands on the occupational therapy perspective and role in caregiver self-efficacy.

2.2 Self-efficacy, caregiver self-efficacy and its impact on the caregiver

Albert Bandura pioneered the concept of self-efficacy in the late 1970's. Self-efficacy refers to the "beliefs in one's capabilities to organize and execute the course of action required to manage prospective situations" and that "efficacy beliefs influence how people think, feel, motivate themselves, and act" (Bandura, 1995, p.2). CSE, a subcategory of self-efficacy, is defined as "beliefs or judgments a parent (caregiver) holds of their capabilities to organize and execute a set of tasks related to parenting a child" (de Montigny & Lacharité, 2005, p.390).

Primary sources impacting self-efficacy that have been featured in literature include: (i) enactive mastery (personal) experience where an individual experiences success in performing a task; (ii) vicarious experience involving observation of another's success in performance; (iii) verbal persuasion by means of others expressing confidence in an individual's abilities resulting in social

[1]Literature for this study was obtained from EBSCOHost and Google Scholar database platforms with the following databases: Academic Search Premier, Africa-Wide Information, CINAHL, ERIC, MEDLINE, PsycINFO, and SocINDEX. The following search terms were used: self-efficacy, parent self-efficacy, parenting competence, HIV, South Africa, trial, parent, caregiver, mother, father, parent training, parent intervention, parent program, group intervention, low income, poverty, parenting self-efficacy measuring instrument, parenting sense of competence scale, general self-efficacy scale, occupational therapy, early intervention, and, early childhood development. Citations within articles supplied further research that did not emerge with the initial search. The ALEPH catalogue in the UCT library was also used to source literature with the search terms: self-efficacy, parent self-efficacy, and HIV.

influence; and (iv) emotional arousal where an individual is influenced by mood and physical status (Bandura, 1997; de Montigny & Lacharité, 2005; Steyn & Mynhardt, 2005). Theoretical application of the sources of self-efficacy are further detailed in section 3.3.4 which discusses the study intervention and describes how the sources of self-efficacy were embedded into the intervention to influence CSE.

In Bandura's review on the functional properties of self-efficacy, he expressed that self-efficacy beliefs influence various processes that contribute to human functioning, namely, cognitive, motivational, affective, and decision-making processes (Bandura, 2011). Thus, self-efficacy beliefs can influence thoughts to be optimistic and self-enabling, or pessimistic and self-debilitating. In turn, the same notion would apply to CSE. Strong CSE beliefs lead to motivated caregivers who persevere when encountering caregiver challenges.

Self-efficacy is also a primary component preceding human agency (Bandura, 1982, 1997; Cervone, Artistico, & Berry, 2006). A self-efficacious caregiver yields an agentic caregiver who is willing to engage in caregiving tasks as a result of their belief in their potential ability to perform such tasks successfully. Caregivers with high levels of CSE are actively involved in stimulating their children's skills. On the contrary, disempowered caregivers, i.e. those who do not believe they are able to produce a certain result, will not attempt to engage with a corresponding caregiving activity (Bandura, 1997). Therefore, caregiver efficacy beliefs shape caregiver behaviour (Bandura, 1995). A review of the potential roles of CSE conducted by Jones and Prinz (2005) affirms a strong relationship between CSE, caregiver competence and positive caregiving practices. This is not a unidirectional relationship but rather a transactional relationship where each factor impacts the other and can have reverse effects (Jones & Prinz, 2005). Therefore, caregivers who become equipped with skills can also feel greater levels of CSE. In relation to this study, being equipped with skills to promote child development, learning and play should consequently influence CSE. Caregivers with high levels of self-efficacy gain various personal benefits. The perception of successful performance in the caregiving role gives way to personal empowerment (Coleman & Karraker, 2003). In addition, high CSE fosters the potential for greater levels of personal investment in the caregiving process as well as behavioural and emotional responsiveness towards the child (Bandura, 1995; Roskam, Brassart, Loop, Mouton, & Schelstraete, 2016). Thus, in addition to CSE facilitating the ability and execution of related caregiving tasks, it also has a widespread effect on

other caregiving variables (Roskam et al., 2016). Conversely, caregivers with low levels of self-efficacy tend to feel overwhelmed and burdened by their caregiving role and duties, and thus become disempowered, further hindering the development of the caregiving role and related skills (Coleman & Karraker, 2003). In summary, caregiver self-efficacy beliefs and perceived ability has a direct impact on caregiver behaviours and actual ability, as well as other caregiver variables, and vice versa. Therefore, it is valuable to explore what interventions can impact CSE.

2.3 Interventions addressing caregiver self-efficacy and their impact on caregiver and child outcomes

Caregiver self-efficacy plays a pivotal role in mediating caregiver behaviour in caregiver-child interactions and thus, has an indirect influence on child development (Ardelt & Eccles, 2001; Bandura, 1995; Coleman & Karraker, 2003; Jones & Prinz, 2005; Pelletier & Brent, 2002). It is well established in literature that a positive correlation exists between CSE and caregiving behaviour and this maximizes opportunities for child development (Coleman & Karraker, 2003). This correlation is bidirectional, in that child outcomes can also influence caregiver-child relationship and CSE. Thus, interventions addressing CSE can also have an impact on child outcomes, and, interventions enhancing child outcomes could also improve CSE. The following question was drawn on to assist the review of the available literature discussing interventions aiming to address parental self-efficacy: *What intervention has been conducted to explore changes in parental self-efficacy [to effect changes in child participation outcomes] in parents of children with and without chronic illness?*

Two systematic reviews were found investigating change in CSE following intervention (Hohlfeld, 2016; Wittkowski et al., 2016). In Hohlfeld's (2016) systematic review examining parent training programmes for children with developmental disabilities and their impact on parental self-efficacy, it was found that CSE had a significant increase across all 21 studies investigated in the meta-analysis. Wittkowski et al. (2016) investigated randomised control trials with group-based intervention for parents with pre-school children. Most of the studies from this review demonstrated a positive effect on CSE from intervention but there was caution highlighted in conclusions in that many studies displayed methodological limitations (Wittkowski et al., 2016). A further recommendation from Wittkowski et al. (2016) was that deeper investigation into the components of interventions that influence CSE should yield better understanding for future practice. These systematic reviews

along with the other literature described below clearly illustrates that caregiver intervention programmes can influence CSE.

Many caregiver-directed interventions that explore change in CSE, address child behaviour in relation to preventing child behaviour problems and promoting positive behaviours in children as well as caregivers to manage child behaviour effectively. Breitenstein et al. (2012) reported enhanced CSE in caregivers from low income communities following a parenting skills intervention when compared to the control group. Caregivers receiving the parenting skills programme were also found to display more positive parenting behaviour, using less corporal punishment and more consistent discipline (Breitenstein et al., 2012). Behaviour problems in these caregivers' children were also reduced following intervention (Breitenstein et al., 2012). Hastings and Symes (2002) investigated changes in parental self-efficacy following participation in a parent-delivered child behaviour programme with mothers of children with autism. This study saw an increase in CSE and suggests that the predicting factors of maternal self-efficacy are based on the extent of support received from the specific programme, autism severity, and maternal stress (Hastings & Symes, 2002). Programme variables, such as the amount of time per week the mother would spend delivering intervention or duration of the programme from the outset, however, were shown to be irrelevant in predicting change in maternal self-efficacy (Hastings & Symes, 2002). A one year follow-up study explored the long-term effectiveness of parenting training focussed on managing child behaviours (Tucker, Gross, Fogg, Delaney, & Lapporte, 1998). The initial study intervention supported parents to ascertain prosocial child behaviour and reduce negative child behaviour through change in parent-child interactions (Tucker et al., 1998). This follow-up study demonstrated the lasting positive effects of maternal self-efficacy and mother-child interactions following intervention (Tucker et al., 1998). A study conducted in Japan implemented a parenting programme, the 123Magic, which sought to build caregiver competence to manage child behaviour (Kendall et al., 2013). The study also revealed significant improvements in maternal self-efficacy following the programme (Kendall et al., 2013). Spoth, Redmond, Haggerty and Ward (1995) conducted a study with an intervention that entailed prevention-focused parenting skills training. The training aimed to enhance parent-child interactions as well as reduce the child's risk of early substance use (Spoth et al., 1995). This study revealed an increase in maternal self-efficacy (Spoth et al., 1995).

In addition to exploring change in CSE, some studies looked at the impact of the intervention on caregiver stress and its relationship to CSE. Bloomfield and Kendall (2012) explored whether changes in CSE following 123Magic parenting programme correlated to changes in caregiver stress and child behaviour. The intervention encompassed 6 weekly parent support groups lead by a trained facilitator. These group sessions aimed to support caregivers to become more effective and confident in their caregiving role of managing child behaviour. During group sessions, caregivers would have opportunities to listen and share caregiving experiences which would be followed by discussion around applying effective techniques to personal circumstances. A primary principle of the intervention programme was to offer support and validation to the caregivers. The findings of this study reveal that this intervention was successful in increasing CSE and decreasing levels of caregiver stress following their parenting programme. This study, as well as others, suggest that there is a correlation between parenting self-efficacy and parenting stress in that, where parenting self-efficacy increases, the experience of parenting stress decreases (Bloomfield & Kendall, 2012; Jones & Prinz, 2005; Sevigny & Loutzenhiser, 2009). In addition to lasting effects on CSE following intervention, Tucker et al. (1998) also found lasting effects on maternal stress. This is of particular significance as the population of caregivers to HIV-positive children residing in low socioeconomic areas are known to have "extremely high" levels of stress (Potterton et al., 2007, p.210). There are similarities in the 123Magic programme compared to PICIHBI conducted in this study in terms of facilitating shared discussion and support. This infers that PICIHBI could influence CSE but it could also potentially influence caregiver stress, although not measured specifically in this study.

There are a few intervention studies that investigate the effect on CSE, with interventions that aim to develop general parent-child interactions. A randomised micro trial conducted by Mouton and Roskam (2015) found that an intervention involving social comparison and positive feedback, informed by social learning theory processes, can improve maternal self-efficacy. Furthermore, positive feedback implemented in the intervention was shown to foster positive behaviours in both mothers and children during parent-child interactions (Mouton & Roskam, 2015). The outcome of positive behaviour referred to in the study was not related to behaviour associated with discipline or managing behaviour problems as the studies mentioned previously. However, the positive behaviour outcomes encompassed maternal emotional responsiveness and behavioural responsiveness to react timeously as needs arose and to support their children in ways that were developmentally appropriate (Mouton & Roskam, 2015). In this study, mothers and children also displayed shared

positive affect and were able to solve problems together. The child also demonstrated greater enthusiasm and persistence towards tasks (Mouton & Roskam, 2015). A randomised control trial conducted by Gardner, Burton, and Klimes (2006) tested the effectiveness of a parenting intervention primarily for low-income families in sites across the United Kingdom. The intervention for the study involved working with parents and addressed child behaviour and general parent-child interactions, covering the topics: parent-child play, praise, incentives, limit-setting, problem solving and discipline (Gardner et al., 2006). The study utilized the Parenting Sense of Competence scale (PSOC) with the subscales of self-efficacy and satisfaction in parenting (Johnston & Mash, 1989). Following intervention, parents felt more confident and reported that their parenting skills had improved. The self-efficacy subscale of the PSOC also demonstrated significant change, however, there was not significant change in the parental satisfaction subscale which would be plausible considering the intervention did not target this construct specifically.

A few studies have been conducted exploring the effectiveness of an intervention teaching caregivers a specific skill, such as massage, to be used at home with their children with disabilities (Barlow, Powell, Gilchrist, & Fotiadou, 2008; Barlow, Powell, & Gilchrist, 2006; Coren, Barlow, & Stewart-brown, 2003; Cullen & Barlow, 2004). The results of the studies reveal a statistically significant increase in parental self-efficacy and management of their child's psychological well-being, following the intervention (J. H. Barlow et al., 2008; J. Barlow et al., 2006; Coren et al., 2003).Some of the above intervention studies reported that there was a difference in CSE outcome between mothers and fathers (Spoth et al., 1995; Tucker et al., 1998). Tucker et al. (1998) further states that the positive significant difference in parent-child interactions and parental stress was limited to mothers only. This suggests that parenting intervention could have a differing effect on CSE (and possibly other caregiver variables) in mothers compared to fathers.

Following the literature search it was evident that there are limited studies investigating change in CSE following caregiver directed intervention that aims to improve child development, learning and play because study interventions tend to address child or parent behaviours or parent-child interactions. However, there was some overlap in the intervention study by Gardner et al. (2006) with the topics previously outlined above that included parent-child play and problem-solving. Occupational therapy specific intervention studies exploring the impact on CSE following caregiver-mediated intervention could not be found. Furthermore, self-efficacy studies investigating an HIV-

positive population are generally in relation to ART adherence or managing sexuality and behaviour in HIV-positive adolescents. Studies could not be found exploring the effect of intervention promoting child development on CSE in caregivers with HIV-positive children. Occupational therapy interventions targeting child development, learning and play are routinely administered in clinic settings where an OT is available. There is a lack of research exploring the efficacy of such interventions and this further motivates the value of investigating the impact of these interventions on CSE.

2.4 Occupational therapy's role in addressing CSE

Progression in occupational performance and engagement can be associated to self-efficacy as it relates to motivation, initiative and perseverance (Case-Smith, 2015). When looking at the Model of Human Occupation (MOHO) (Kielhofner, 1980a, 1980b; Kielhofner & Burke, 1980; Kielhofner, Burke, & Heard, 1980), one can think of the occupational role behaviours of caregiving constituting interconnected subsystems, namely: habituation, performance capacity, volition and the environment. Within the volitional thoughts and feelings, the MOHO describes a subcomponent of personal causation as "one's sense of capacity and effectiveness" (Kielhofner, 2008, p.13). Self-efficacy is deemed a contributing element to personal causation, encompassing "thoughts and feelings concerning perceived effectiveness in using personal abilities to achieve desired outcomes in life" (Kielhofner, 2008b, p.47). One can see the close association to self-efficacy theory when looking at beliefs regarding skills and capacity to carry out the occupational behaviours as related to the MOHO (Henry & Coster, 1997; Kielhofner, 2008). Caregiver self-efficacy can be seen as beliefs that a caregiver holds about their effectiveness in the occupation of caregiving, contributing to occupational performance in fulfilling the caregiving role.

Occupational therapists can provide intervention that equips clients with skills through providing opportunities to engage in occupations and facilitating mastery of the skills. The therapist can also enhance beliefs in competence through this engagement process and provide positive feedback. Mastery experience and verbal persuasion through feedback are two sources of self-efficacy (Bandura, 1997). With expertise in child learning, development and play, occupational therapists can help provide caregivers with opportunities and suggestions to actively develop skills to promote child outcomes. Increasing caregiver skill and ensuring caregivers experience success in activities

with their children will influence their self-efficacy beliefs. Occupational therapists have shown success in providing early childhood development intervention that is family-orientated through occupational performance coaching (Graham, Rodger, & Ziviani, 2009; Kingsley & Mailloux, 2013). Empirical data involving occupational therapy specific intervention that manipulates caregiver self-efficacy is, however, limited, and thus contributing towards evidence-based practice in this field of occupational therapy is valuable.

2.5 Conclusion to literature review

There is an absence of empirical studies exploring changes in CSE as a result of caregiver directed interventions that focus on promoting child development, learning and play. The majority of the interventions have addressed CSE to effect more positive behaviours in their children. There was also a significant paucity of literature detailing interventions that enhance self-efficacy in the domain of caregivers of children with HIV. Furthermore, there is no literature exploring these components and their relationships in the domain of paediatric occupational therapy. However, there is sufficient empirical data based on other types of parenting skills interventions and populations to suggest that caregiver-directed intervention can influence CSE.

3 Intervention

3.1 Introduction to intervention

This chapter presents the two types of interventions administered to the caregiver-child dyads. The control group received one-on-one OT treatment with an OT working directly with the child and focused on child-specific outcomes. This type of treatment was based on what the OT would usually do in similar clinic settings to enhance learning, development and play. The experimental group received play-informed, caregiver-implemented, home-based intervention (PICIHBI). PICIHBI focused on equipping caregivers with skills to promote learning, development and child playfulness, and enhancing CSE to execute these skills. PICIHBI sessions comprised of a discussion and knowledge transfer component with the caregivers and another component of experiential learning and coaching that also included the children. PICIHBI was developed by the researcher along with other Kidzpositive OTs and research colleagues. The details of the two types of intervention and development of PICIHBI are further discussed in this chapter. A summary of the similarities and differences of the interventions can be found in Table 1 at the end of the chapter.

3.2 Control group intervention

Intervention received by the control group comprised of conventional one-on-one OT treatment sessions typically found in a governmental clinic setting in South Africa.

3.2.1 Structure and facilitation of the control group intervention

Occupational therapists were employed by Kidzpositive specifically to run this intervention. The best available candidates with relevant paediatric experience were hired as agreed by the collateral research team and Kidzpositive staff. The OTs hired to run this intervention were not given specific intervention to conduct but rather briefed to use their usual OT reasoning and skill to conduct therapy to improve child outcomes as indicated in the baseline assessment and based on any further learning, development or play limitations that were picked up during the intervention process. These OTs had access to all the assessment results which gave an initial indication of child specific needs.

There were 10 monthly individual OT appointments made available to participants, of 45 minutes each. The specific child outcomes and performance components were the main focus of this intervention with the OT working directly with the child. The caregiver was provided the opportunity to sit in on the session and the OT could liaise with the caregiver as needed. However, sometimes the caregiver did not want to sit and stay in the session for various reasons including preferring to instead wait in the waiting room for their own doctor's appointment or to go to the pharmacy to fetch the child's medication. Therefore, the caregiver might not have always been in the session. The therapist's intervention sessions typically involved therapeutic activities according to the specific child's needs and goals. The therapist would liaise with the caregiver where possible to attain more information about the child and give some advice and talk about activities to do at home. However, this was not the main focus of the intervention sessions.

3.2.2 Take home items

Administering items for use at home was not specifically part of this intervention. However, the control group OTs reasoned that they wanted some children to do more drawing, cutting or ball skills at home and related items were not possessed by the family. These items were administered on an as needs basis to specific children. Items administered were limited to only balls, crayons, scissors and paper that were donated to Kidzpositive. The majority of the participants did not receive items during the intervention period.

3.3 Experimental group intervention

The experimental group received PICIHBI administered by the researcher of this study. This intervention has not yet been published in literature but the details of development guided by clinical reasoning and literature will be described.

3.3.1 Development of PICIHBI

PICIHBI was designed by researchers and Kidzpositive Family Fund occupational therapists, of which the primary investigator of this study was one, working at various governmental out-patient paediatric HIV clinics in the Cape Town Metropole. PICIHBI was developed in a response to the challenges experienced as outlined in chapter 1.2. As mentioned previously, results from the study

conducted by Ayliffe et al. (2013) exploring play perceptions and knowledge of caregivers with HIV positive children attending Groote Schuur Hospital (GSH) and other clinics informed the development of PICIHBI. The study indicates that caregivers saw play as an important means to learning and development but knowledge about play was limited. This gave a leverage point in the intervention to draw on the caregivers' known value of play and building on skills in this area. This led to the "play-informed" emphasis in naming the intervention for research. PICIHBI was given the marketing name of "GOKIDZ" standing for 'Guiding Opportunities for Children', which was used with the caregivers and for funding purposes. Prior to this study, the researcher and colleagues administered PICIHBI with patients and caregivers from other HIV clinics who had similar demographics and contextual challenges. During this phase, as well as the study intervention phase, the therapists would meet regularly to give feedback on implemented intervention and apply gained insight to effectively refine strategies and the programme.

3.3.2 Aims and objectives

The primary aim for the group-based intervention was to foster child development, learning and play, mediated through caregivers.

Other objectives for the caregiver receiving PICIHBI included:

- To increase caregiver awareness of the child's current abilities and what is expected of the child at a particular age and grade (for school-going children)
- To enhance caregiver-child interaction to foster good, nurturing and playful relationships between the child and caregiver which would consequently influence positive child outcomes
- To transfer knowledge for greater understanding around child learning, development, play and related skills
- To equip caregivers with activity resources, ideas and means of grading activities to promote child learning, development, play and self-care in the daily routine
- To provide a space for incidental psychosocial support in the group as needed in relation to caregiving for a HIV-positive child.
- To provide support and assistance in accessing information, services and resources to further support the caregiver's efficacy to promote learning, development and play of their children.

- To provide a space for active participation for caregivers to share and discuss with each other, their challenges, ideas, and ways of promoting child learning, development, self-care and play.
- To create a sense of autonomy in the caregivers to take initiative in the sessions and use their own resourcefulness and modelling for other caregivers.
- To improve caregiver problem-solving skills and creative thinking to be able to apply and adapt learning to the caregiver's specific child and context and maximise on opportunities in the environment and daily routine to promote learning, development and play.

Objectives for the children receiving PICIHBI included:

- To progress in development, seen by progression in developmental activities assessed by the Griffiths Mental Development Scales (ARICD, 1996, 2006)
- To support progress in academic learning
- To progress in playfulness, as seen through the Test of Playfulness (Bundy, Nelson, Metzger, & Bingaman, 2001)
- To develop independent thinking with an emphasis on the development, learning or play process more than a specific activity outcome
- To foster self-motivation to engage in development, learning and play activities with the caregiver

3.3.3 Structure and facilitation of PICIHBI

This intervention was facilitated by the researcher, a qualified occupational therapist. In addition, PICIHBI included the use of a group assistant who could provide translation in isiXhosa and English. The group assistant had been employed by Kidzpositive for a few years and knew the context of the Groote Schuur out-patient HIV clinic well. The assistant had a similar background and demography to that of the typical caregiver participants and could easily identify with them.

The intervention developers decided to format the sessions around a particular child outcome or skill as the topic for each session, such as gross motor skills or numeracy skills. Exploring these topics with the caregivers was the means through which the PICIHBI objectives could be achieved. For the breakdown of the various session topics see Appendix I: PICIHBI (or GO KIDZ) session structure and

GO Box examples . The participants were divided into age-bands according to the child's age so that the caregiver could receive guidance which was age-appropriate. These age bands were 6 months to 2 years 11 months; 3 years to 5 years 11 months; and 6 years to 7 years 11 months at time of baseline data collection. The latter group corresponded with children in grade R to grade 2. The content and focus of child outcomes within the intervention sessions was guided by literature indicating learning, development and play concerns, particularly literature concerning HIV-positive children in low income settings in South Africa (Potterton et al., 2007; Potterton et al., 2009; Potterton, Stewart, Cooper, & Becker, 2010). Occupational therapy assessment results and intervention conducted at the various HIV clinics where PICIHBI was being facilitated (including baseline results of the parallel studies conducted at Groote Schuur Hospital) also informed priority areas and intervention content to be explored. In addition, the older child age group content was guided by South Africa's National Curriculum and Assessment Policy Statement (CAPS) to align with the demands and requirements at school. Many of the sessions for this older group incorporated information to build on the caregivers' awareness of the CAPS requirements. Many of the caregivers were unaware of these details and found it helpful to understand more detail of what their child was doing or should be doing at school.

PICIHBI was administered in groups of approximately 5 dyads. The participants had 10 monthly appointments afforded to them. Each session was approximately 1.5 hours. The first 45 minutes of the session comprised only of the caregivers and facilitators, and included: feedback on implementation from previous session, activities with the caregivers, adult learning, knowledge transfer, and discussion around skills needed for child-rearing and child development, learning and/or play. For the second 45 minutes, the children joined the session for practical activities where the caregivers could apply what they had learnt and discussed in the first half of the session. During this time the caregiver would work directly with the child while the therapist monitored, gave feedback and guided interaction. The therapist only worked directly with the child for modelling purposes so that the caregivers were the primary players working directly with their children.

3.3.4 Sources of self-efficacy informing PICIHBI

Bandura's (1997) identified sources of information that influence self-efficacy were recognised to be incorporated into parenting programmes to alter levels of parent (or caregiver) self-efficacy. The

design and principles established in PICIHBI have drawn on these sources to affect change in CSE. As mentioned, the four main sources that influence self-efficacy include: (i) enactive mastery (personal) experience where an individual experiences success in performing a task; (ii) vicarious experience involving observation of another's success in performance; (iii) verbal persuasion by means of others expressing confidence in an individual's abilities resulting in social influence; and (iv) emotional arousal where an individual is influenced by mood and physical status (Bandura, 1997; de Montigny & Lacharité, 2005; Steyn & Mynhardt, 2005).

Enactive mastery (personal) experience

Integral to the design of PICIHBI sessions is the experiential component where the children join the session and the caregivers can work directly with their children, applying ideas, strategies and skills explored earlier in the session. This provides an opportunity for the caregiver to experience immediate success in their interaction. Under the guidance and support of the occupational therapist, there is greater probability of a successful experience. Bandura (1997) deems this source of self-efficacy as the most influential experience of all the sources to change self-efficacy. Similarly, the OTs agreed that it was important to incorporate an experiential component to guide success during the PICIHBI session as to enhance CSE and increase likelihood of carryover of the enactment of the successful experience into the caregiver and child's home life.

Vicarious experiences

The nature of the group format in PICIHBI allows for caregivers to not only observe the OT but also the assistant and other caregivers' success in engaging with their children. Vicarious experiences have a stronger impact when the observer can more closely identify with the model (Bandura, 1997). Having a group where caregivers could more closely identify with each other rather than only an "expert professional" typically from a different background, was a notable difference in practice. In addition, another important consideration around the intervention was the facilitator(s). As the group of Kidzpositive OTs employed to facilitate the intervention comprised of white, English speaking females from mid to high income backgrounds, there was a marked difference to the general demographic of the caregivers. Some of the OTs also did not have their own children. With this in mind, the demographic and cultural difference was highlighted and the OTs implored to remain cognisant of this through the design process. One of the key decisions made in the

facilitation of PICIHBI was to have an assistant that could serve not only as a translator but as someone who the caregivers could identify more with as someone from a similar background facing and having faced similar challenges of rearing children in low income contexts. The occupational therapist would lead the facilitation of the groups. The assistant augmented the role of the facilitator in that they assisted with translation of the group content and also added their own perspective of being a mother/grandmother. The assistant also served as a model and an active participant in the group, interacting with the children when appropriate. The relationship between the assistant and the OT was that of ensuring cultural appropriateness and sensitivity of the intervention. Thus, having an assistant with whom caregivers could more closely associate themselves, helped to also provide a modelled way of practice and vicarious experience to enhance CSE.

Verbal/social persuasion

Verbal persuasion was applied in the structure of the sessions through the designated time for discussion and feedback with caregivers about what had happened since the previous session. Encouragement and positive affirmation was also an important principle for the therapist to apply during feedback in the experiential component of the session. It was proposed that the therapist would encourage caregivers to also affirm each other to create an environment of encouragement and affirmation, rather than just employing a unilateral sense of encouragement.

Emotional/physiological arousal

The multiple challenges facing the caregivers could easily lead to a stressful physiological state which could hinder the experience of success (Bandura, 1986). Although psychosocial support was not a main objective of PICIHBI, the OTs recognised the multiple psychosocial stressors of rearing an HIV-positive child in impoverished circumstances that could affect CSE and performance of caregiving (J Potterton et al., 2007; Richter et al., 2009). Thus, the approach in PICIHBI allowed for flexibility in providing psychosocial support as needs arose in the group to effectively manage negative emotional arousal. Through piloting PICIHBI, observation and feedback illustrated that caregivers would experience the therapeutic factor of universality where caregivers were relieved at not being alone with their challenges as other caregivers shared similar thoughts, feelings and problems (Yalom & Leszez, 2005). The empirical observation was that the more caregivers would share and

learn about each other's similar challenges, the more they would become trusting and open in the group (Yalom & Leszez, 2005). This would lead to a truer and more effective response to the challenges experienced among the caregivers in promoting learning, development and play.

3.3.5 The GO Box

As part of the intervention, caregivers were supplied with a stimulation toolkit called a "GO Box". The GO Box was built up between sessions as various materials were administered for the caregiver to take home and continue to engage in some of the suggested activities. Although there are differences of opinion with regards to providing equipment, the PICIHBI design team reasoned that providing a tool kit would be beneficial particularly because the caregivers come from low income settings as they do not have many basic items, such as crayons and balls, that would promote particular learning, development and play skills in the child. However, the principles of the GO Box materials included having items that were low cost and incorporated homemade toys. As PICIHBI was divided into child age categories, each age category received a different GO Box consisting of age and developmentally appropriate items. The decision on the contents of the box was based on covering skills sets aligned to the intervention sessions. Literacy items, such as the children's books, were administered according to the home language with a choice of English, Afrikaans and isiXhosa. The therapists sourced the items that would be the most cost-effective but also maximise on effective learning, development and play. The GO Boxes also came with a caregiver file for caregivers to insert activity ideas, resources or notes from the sessions. To see an example of a GO Box and its contents, refer to Appendix I: PICIHBI (or GO KIDZ) session structure and GO Box examples.

3.4 Key similarities and differences between the interventions

Table 1 illustrates a summary of the key differences between the interventions received by the control group and experimental group.

Table 1: Key similarities and differences between the two interventions

Variable	Control Group	Experimental Group
Intervention received	Conventional one-on-one OT	PICIHBI
Primary goal of intervention	Enhance child specific outcomes of development,	Equip caregivers to enhance child outcomes of

	learning and play	development, learning and play
Frequency of sessions	Once a month	Once a month
Total number of sessions offered to participant	10	10
Number child-caregiver dyads participating in a session	1	5 - 6
Caregiver participation	Secondary, not required to be in session but may be involved as the therapist or caregiver see fit.	Primary focus of therapist
Child participation	Primary focus of therapist	Secondary focus of the therapist, involved in experiential component with caregiver working directly with child
Session time	45 minutes	1.5 hours: 45 minutes with caregivers and 45 minutes with caregiver-child dyads
Total intervention time	7.5 hours	15 hours
Translator and assistant	Not present	Present as part of practice
Materials	Therapy resources predominantly used within session at clinic only. Administration of items not specifically part of intervention but a few exceptions had basic items administered on an as needs basis.	GO Box with activity resources administered for in session and home use.

3.5 Conclusion to Intervention

The study investigates two types of intervention, conventional one-on-one occupational therapy directed at the child and PICIHBI which is a group-based intervention directed at the caregivers. Both interventions aim to promote child development, learning and play but a key difference is that PICIHBI is mediated through caregivers and additionally develops caregiver skills. Another key difference with PICIHBI, is that a stimulation tool kit, “the GO Box”, was also administered to caregivers for use to implement intervention at home with their children. PICIHBI was developed by a group of occupational therapists who administered the intervention at various other sites and continually reviewed and developed the intervention prior to and during the study period.

4 Methodology

4.1 Introduction to Methodology

This chapter describes the study design in more detail, as well as the clinic setting and sample criteria for the caregiver participants. This is followed by describing the recruitment of participants in the study, randomisation process, data collection methods, outcomes measures used and analysis procedures. The chapter finishes with the ethical considerations upheld in the study.

4.2 Research Trial Design

This pragmatic study utilized a single centre, single blinded, stratified (caregivers with children aged 6 months to 5 years and caregivers with children aged 6 to 8 years), randomised control (1:1), parallel-group design. The study design sought to assess the non-inferiority of the effectiveness of PICIHBI received by the experimental group when compared to the effectiveness of the conventional treatment received by the control group. Please see Appendix B: CONSORT checklist for the information included in reporting a randomised trial.

This study design has several advantages for which it has been chosen. The randomisation of this study design limits the potential for allocation bias and generates two comparable groups (Friedman, Furberg, & DeMets, 1996). In addition, the randomisation assures the validity of statistical tests of significance (Friedman et al., 1996). A three-armed randomised control design was initially considered with the third arm including a participant group not receiving intervention. However, this was not utilised for the following reasons:

- The study was subsidized by funders who are primarily interested in funding the provision of intervention.
- If children were found to have significant delays following their baseline assessments, indicated from parallel research, ethically, the children would need to be referred for intervention.
- If intervention for a third group was withheld until the study was completed, the group could wait up to 2 years considering the duration of assessment, intervention, and

pragmatics. This would have been a considerable time for intervention that would be lost for the child.

- A third group would have also diminished the size of the groups which would negatively influence statistical significance.

A pragmatic trial design has been chosen to consider the effect of an intervention approach in a real clinical setting in order to inform further practice in similar settings (Alford, 2007). The pragmatic trial design has guided the nature of inclusion/exclusion criteria leading to a more heterogeneous sample. It also informed the nature of the control group intervention to be occupational therapy treatment currently received in practice.

A non-inferiority study design allows for comparison of the two interventions to determine whether the new intervention is not inferior in the outcome of interest compared to the conventional intervention. Although the effectiveness of the particular occupational therapy intervention administered in a clinic setting is not established, it is routinely administered in paediatric clinics where an OT is based. Indirect evidence demonstrates that occupational therapy can improve child outcomes (Case-Smith, Clark & Schalbach, 2013; Clark & Schlabach, 2013; Polatajko & Cantin 2010) lessening the burden on caregivers. A systematic review conducted by Kuhaneck et al. (2015) also indicates that centre-based intervention can improve CSE. A non-inferiority study was chosen in consideration of the contextual challenges of treatment provision outlined in the problem statement. Thus, with non-inferior levels of CSE established, PICIHBI would be the more beneficial intervention in relation to the added advantages including: gaining a larger reach of the population, lower cost of intervention, more efficient use of human resources and more direct benefits to the caregiver in their role. The null hypothesis is that the values of the dependent variable (CSE) of the parents attending the PICIHBI intervention are inferior to the CSE values of the existing intervention. If the null hypothesis can be rejected it would indicate that the PICIHBI intervention is not inferior to the conventional intervention. The hypothesis is such that PICIHBI will not be appreciably worse than the conventional clinic-delivered occupational therapy intervention in CSE at 12 months. Another consideration in this decision to opt for this design was that non-inferiority does not preclude establishing superiority (Vavken, 2011).

4.3 Aim

The aim of the study is to determine if the CSE levels in a group of caregivers of HIV-positive children aged 6 months to 8 years 0 months on ART, after receiving play-informed caregiver-implemented home-based intervention (PICIHBI) are not inferior to CSE levels in an equivalent group of caregivers with children receiving conventional one-on-one occupational therapy.

4.4 Objectives

The primary objective was to:

- determine if there is a comparable change in CSE on the Parenting Self-Efficacy Measuring Instrument (P-SEMI) (Harty, 2009) in caregivers receiving intervention in the experimental and control groups between baseline, mid-test and post-test.

The secondary objectives were to:

- describe CSE and general self-efficacy of the participants at baseline prior to intervention using the Parental Self-Efficacy Measuring instrument (P-SEMI), the Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978) and the General Self-efficacy Scale (GSE)
- establish the change *within* the experimental and control groups within the P-SEMI subscales (showing affection and empathy, engaging in play, facilitating routines, establishing discipline strategies, providing appropriate activities for learning and development, and promoting communication interaction) between assessment points.
- establish the change *between* the experimental and control groups within the P-SEMI subscales (showing affection and empathy, engaging in play, facilitating routines, establishing discipline strategies, providing appropriate activities for learning and development, and promoting communication interaction) between assessment points.
- determine the change in self-efficacy using secondary measuring instruments: the Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978) and the General Self-efficacy Scale (GSE) *within* the experimental and control groups.
- determine the change in self-efficacy using secondary measuring instruments: the Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978) and the General Self-efficacy Scale (GSE) *between* the experimental and control groups.

4.5 Hypotheses

The null-hypothesis for the study is that PICIHBI will be inferior to conventional one-on-one occupational therapy intervention in its ability to improve levels of CSE in caregivers with HIV-positive children aged 6 months to 8 years on ART, measured after 1 year of intervention.

The alternative hypothesis is that PICIHBI will have comparable influences on levels of CSE in caregivers with HIV-positive children on ART aged 6 months to 8 years, compared to caregivers whose children are receiving conventional one-on-one intervention, measured after 1 year of intervention.

4.6 Research Setting

The study was conducted in an out-patient paediatric HIV clinic situated at Groote Schuur Hospital (GSH), a governmental hospital in Cape Town, South Africa. Research participants were familiar with the site environment as it was their usual clinic site where they receive regular follow ups with their doctors and other health services as well as collect their ARVs every month. The population attending the clinic typically resides in low income areas not within walking distance of the hospital. Participants usually make use of taxi services for transport to the clinic and thus require transport money to attend the clinic which can be difficult for financially constrained families. This clinic was supported by Kidzpositive Family Fund (Kidzpositive), a non-profit organization. Kidzpositive provides complementary services such as occupational therapy, counselling, and income generation projects, to families attending governmental HIV clinics. The researcher of this study was employed by Kidzpositive to work as an occupational therapist at the GSH clinic as well as at other sites where PICIHBI was first piloted. Therefore, prior to commencement of the study, the researcher had a good understanding of the environment and patients, as well as established relationships with key clinic staff members to support the research. One of the services rendered by Kidzpositive is to assist with transport funds to and from the clinic. However, it does not always cover the entire transport cost for the caregiver and child, depending on the distance travelled. The challenge of transport cost is one of the factors that impedes clinic attendance which will be further discussed. Please refer to Appendix D for the letters sent for permission to conduct research at GSH.

4.7 Participant Selection

4.7.1 Population

The population for this study consisted of primary caregivers, with HIV-positive children on ART born between 2007 to 2013 (children older than 6 months up to 7 years at the time of the pre-test in 2014), and attending the out-patient paediatric HIV clinic based at GSH. This study aimed to recruit the entire population of caregivers that fit the participant criteria. The population number at the time of recruitment was 142 caregiver-child dyads.

Known typical characteristics of the population included:

- caregivers that are biological mothers or grandmothers of children attending the clinic,
- caregivers that reside in a low income, informal settlements,
- biological mothers that are also HIV-positive and attending the clinic for their own health needs, and
- caregivers with isiXhosa as their home language.

4.7.2 Inclusion criteria

To be included in the study caregivers needed to:

- care for children born from January 2007 to June 2013 who are HIV-positive on ART
- accompany their children who attend the out-patient paediatric HIV clinic at GSH
- spend at least 7 waking hours a week with their children

4.7.3 Exclusion criteria:

Caregivers were excluded from the study if they:

- did not have legal authority to give consent
- could not commit to at least 5 of the 10 monthly sessions at recruitment.
- were employed by home care facilities to take care of children
- were secondary caregivers to a child where a primary caregiver had already been enrolled as the participant in the study, thus drawing on only one caregiver per child in the population.

4.7.4 Sample size

The study aimed to recruit the entire population (*N* = 142, *n* = 71 per group) to attain the greatest confidence intervals, however, the sample size was calculated to determine the number of participants required for a 95% confidence interval. Sealed Envelope Ltd. (Sealed Envelope Ltd, 2012), an online sample size calculator, was used to calculate the sample size. The P-SEMI, as the primary outcome measure, has not been used in trials thus far and therefore data was not available to indicate what degree of change in P-SEMI scores would represent a significant difference. Thus, calculations were based on data from a study by Hayes, Matthews, Copley, & Welsh (2008) that used the total mean score from the PSOC, this study's secondary measure, to set the non-inferiority limit to 4 points. It was determined that 68 participants (34 per group) were needed to demonstrate no difference in CSE between PICIHBI and conventional occupational therapy with a 95% confidence interval.

4.7.5 Recruitment and enrolment

Caregiver participants were recruited from the paediatric HIV clinic based at GSH. The researcher, who also worked at the clinic, and had permission to access information in the clinic files, created a population database of the children (and their caregivers). To equate the desired age band for the study, i.e. 6 months to 7 years at the time of pre-test, the database included all the children born between the eligible years (2013-2007). The database included the child's name and date of birth along with the caregiver details such as name and relationship to the child if this information was present. The database provided an organizational system during recruitment to be able to track those already recruited and those who still needed to be approached for recruitment.

Caregivers that fit the selection criteria were recruited individually at the clinic on their children's usual appointment days. The study was explained verbally to the caregivers and an information letter (Appendix E) was given to the caregivers to sign to indicate that they understood the study explanation and that relevant questions had been answered. The caregivers could choose to have the written documentation and study explained in English, Afrikaans or isiXhosa. The researcher was proficient in English and Afrikaans for recruitment. A translator was present to translate into isiXhosa. Caregivers with limited literacy levels were afforded the opportunity to have the written documentation read out aloud to them. When there was more than one caregiver accompanying a

child, the researcher and caregivers discussed who the participant in the study would be based on what was most feasible for the family in line with the selection criteria. Once a caregiver signed the consent form and was enrolled, a baseline assessment appointment was negotiated and detailed on an appointment card for the caregiver. If convenient, the caregiver had the opportunity to carry out the baseline assessment immediately after recruitment process at the clinic. For scheduled assessments, an SMS message was sent a day or two prior to the assessment appointment to remind caregivers of the appointment.

Participants who were on the clinic database but not seen at the clinic during the 3 month recruitment period, were contacted telephonically. The project was explained in the caregivers' preferred language (English, Afrikaans or isiXhosa), and verbal consent was attained. A baseline assessment appointment was verbally agreed with an SMS confirmation message following the telephonic conversation. This confirmation message substituted the appointment cards that were given to caregivers recruited at the clinic and was in addition to the reminder SMS sent prior to assessment. At the baseline assessment appointment, written consent was completed before the assessment commenced. As the intervention of the study involved the caregiver and the child, assent was also attained from children aged 7 (Appendix E).

Caregiver-child dyads who did not attend their baseline appointment were followed up to confirm continued interest in participating in study and a re-scheduled assessment appointment was determined if the caregiver continued to show interest. If a caregiver-child dyad did not attend an assessment appointment after re-scheduling three appointments, they were not enrolled into the study.

4.7.6 Randomisation

During recruitment, the participants were made aware of the two types of intervention and that they would be randomly assigned to one of the two interventions following baseline assessment. Therefore, neither participants nor assessors knew which group they would be allocated to at the time of baseline assessment.

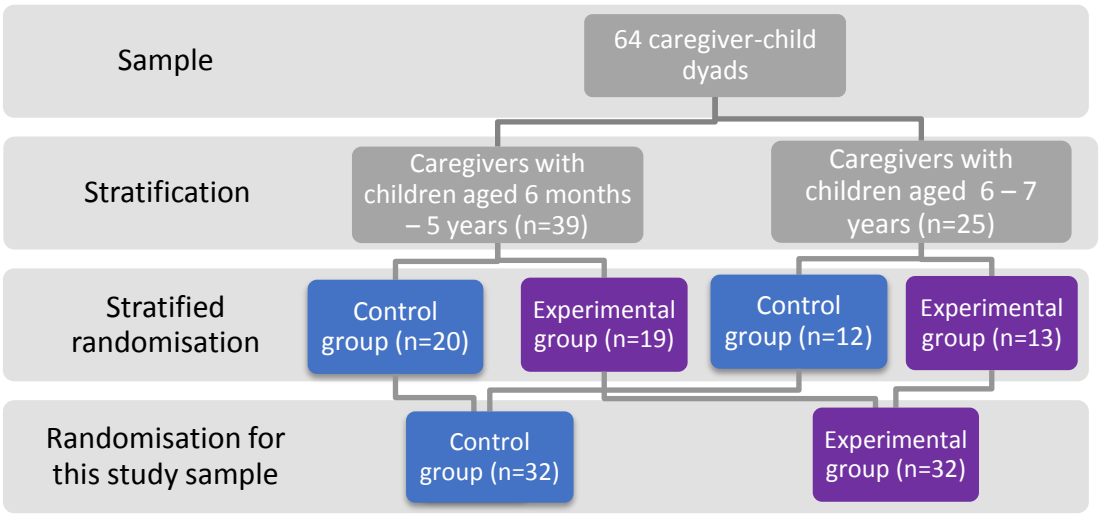
Simple randomisation of the total sample of 64 participants would have been the preferred method to use for this study as it provides a more unpredictable outcome and has superior levels to preclude bias. However, stratified randomisation was decided upon using child age-bands corresponding to the different participant age-bands. An advantage of using stratified randomisation from the intervention perspective was that stratified randomisation helped to provide a better balance between the intervention age groups in PICIHBI.

The caregiver-child dyads were stratified into two child age-bands according to the child's birth year as follows:

1. Children born between January 2009 and December 2013 (children older than 6 months at the start of intervention to children turning 5 years of age in 2014, *n* = 39).
2. Children born between January 2007 and December 2008 (children turning 6 and 7 years of age in 2014, *n* = 25).

See Figure 1 for a visual representation of the randomisation process.

Figure 1: Stratified randomisation process



At the baseline assessment, each participant was assigned a participant code by the assessors which was captured into an online programme, Research Randomizer (Urbaniak & Plous, 2013). A co-researcher involved in the larger study used Research Randomizer to assign the participants a numerical randomisation code. Using Random Sequence Generator (Randomness and Integrity

Services Ltd., 2016) separately for each stratified group, the randomisation codes were randomly assigned between two columns representing the experimental and control groups with a 1:1 allocation. A third party, not involved in the administration of the assessments, conducted the randomisation process.

The assessors were blinded to group allocation until after post assessment data was collected. The researcher of this study assisted with baseline assessment and remained blinded until all baseline data had been collected. The researcher changed roles from baseline assessor to intervention therapist carrying out PICIHBI and did not assist further with mid or post data collection to prevent bias, as she was no longer blinded.

4.8 Measurement Instruments

A demographics questionnaire was developed and administered to participants and 3 measurement instruments were used to measure CSE and general self-efficacy, namely: (i) the Parenting Self-Efficacy Measuring Instrument (P-SEMI) (Harty, 2009); (ii) The Parent Sense of Competence Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978); and (iii) the General Self-efficacy scale (GSE) (Schwarzer & Jerusalem, 1995). The P-SEMI, as a task-specific measure that was validated with a South African sample, was chosen as the primary measurement instrument. The PSOC and GSE, as more widely used instruments, were included as secondary instruments. The secondary instruments are more generalised in measuring the parenting domain (PSOC) and global self-efficacy (GSE).

Demographics questionnaire

A single, comprehensive demographics form (Appendix F: Demographic questionnaire) was developed to capture demographic information relevant to all the specific research studies linked to the sample. Variables that have been reported in literature as determinants or influences of CSE were considered and included for this study. These included demography of caregiver age, gender, relationship to the child, economic status, education, employment status, living conditions, and familial support. In addition, the researcher added an item on this form as to how the caregiver perceived the level of their child's learning, development and play on a 5-point Likert scale.

Parenting Self-efficacy Measuring Instrument (P-SEMI)

A self-administered questionnaire was chosen as the primary outcome measure of CSE. A self-administered instrument was deemed appropriate for measuring self-efficacy as the construct involves self-appraisal and perception and thus does not involve external evaluation. There are several advantages of using a questionnaire as a measuring instrument. Questionnaires are relatively simple to adapt for any purpose or group of people and can be easily administered (Hicks, 2009). Self-administered questionnaires also reduce the potential for the researcher to influence the participants' responses (Hicks, 2009).

Specifically, the study primarily utilized an adapted version of the Parenting Self-efficacy Measuring Instrument (P-SEMI), developed by Harty (2009), to measure CSE. See section A in Appendix G: Combined self-efficacy measures, for a copy of the instrument used in the study. The P-SEMI is a task-specific parenting self-efficacy measuring instrument. It was developed as a response to conceptual and validity concerns with existing instruments intended to measure parenting self-efficacy. The P-SEMI was validated with a South African population of 79 mothers of 3 to 7 year olds. The majority of these mothers completed grade 12 (*N* = 71), were married (*N* = 65) and employed (*N* = 60) (Harty, 2009). Forty-seven of these mothers had typically developing children and 32 mothers had children with various disabilities including developmental disabilities such as Down syndrome, autism spectrum disorders and physical disabilities such as cerebral palsy. The format of the instrument consists of a 6-point Likert scale, self-administrated questionnaire. The P-SEMI measures six parenting sub-domains:

1. showing affection and empathy;
2. engaging in play;
3. facilitating routines;
4. establishing discipline strategies;
5. providing appropriate activities for learning and development; and
6. promoting communication interaction.

Internal consistency has been established for all subdomains between .8 and .91 (Harty, 2009). A strong correlation was achieved with the PSOC (.73 for total scale and .69 for the self-efficacy sub-scale) and a moderate correlation with the GSE (.58) (Harty, 2009). The P-SEMI has been selected for this study for its conceptual construct and validity with a South African population akin to the

population in this research. The P-SEMI was also selected as it is particularly applicable to measuring self-efficacy of caregivers of children below the age of 8.

Parenting Sense of Competence Scale (PSOC)

The Parenting Sense of Competence Scale (PSOC) (Gibaud-Wallston & Wandersman, 1978, cited in Johnston & Mash, 1989) was used as a secondary measure. The 17 PSOC items (Appendix G: Combined self-efficacy measures section B) are recorded on a 6-point Likert scale and are grouped into two-subscales, namely, parental efficacy (*n* = 8) and parental satisfaction (*n* = 9). The PSOC holds sufficient internal consistency with alpha scores of the .79 for the overall scale, .75 for the satisfaction subscale, and .76 for the efficacy subscale (Johnston & Mash, 1989). Nine items are reverse scored in the scale to prevent acquiescence bias (Johnston & Mash, 1989).

General Self-Efficacy Scale (GSE)

The GSE measures a global sense of self-efficacy and is not specific to parenting (Schwarzer & Jerusalem, 1995). It is widely used to help determine how the participant copes with daily life challenges and their resilience to stressful events (Okeke, 2016). The instrument comprises of 10-items on a four-point Likert scale with a Cronbach alpha range of 0.76 to 0.90 (Okeke, 2016). For this study, the instrument was adapted to a 6-point Likert scale following the same format as the Likert scales from the P-SEMI and PSOC. See Appendix G: Combined self-efficacy measures for the adapted version of the GSE used in the study.

Adaptations and translation of instruments

The PSEMI, PSOC and GSE measures were combined into one questionnaire form for administration (Appendix G: Combined self-efficacy measures). Keeping the integrity of the questions in mind, the combined instrument underwent minor adaptations or rephrasing to be simpler and more easily understood by the specific population (see Table 2 for the changes made). The questions were reviewed and analysed to determine what words or questions could potentially be confusing or ambiguous for the caregivers in the population. The questions were also reviewed with a colleague at the GSH Clinic who had similar characteristics to the caregivers in the population, and knew the culture and literacy levels of the population well. The adapted version underwent peer review by

individuals with expertise in self-efficacy and necessary changes were made while at the same time ensuring that content validity was upheld.

The adapted version of the combined instrument was piloted at Beautiful Gate, a non-profit organization in Lower Crossroads, Cape Town to test the administration process of the instrument. This was conducted with 13 selected caregivers (10% of the study population) referred for occupational therapy at Beautiful Gate from the Crossroads paediatric HIV clinic. These caregivers and children were currently being seen for occupational therapy by the researcher at Beautiful Gate. See Appendix D: Permission letters to conduct research to institutions for the letter to Beautiful Gate for approval to conduct the pilot study. These caregivers had similar characteristics to the study population and were thus chosen for the pilot study. When the caregivers and children came for their usual occupational therapy sessions at Beautiful Gate, the pilot study procedure and form was explained and consent was attained. The caregivers completed the forms and any difficulties or questions raised were noted. The outcome of the pilot informed the procedural steps of administration as well as information to be included in the creation of the administration memo. The pilot also led to the development of an administration memo which included possible questions the caregivers could ask and appropriate responses for the assessor. In addition, further edits to the form were completed to enhance the clarity of instructions and questions as well as improve the structure of the form. Following administration of the combined instrument, the scoring of the instrument and capturing of the data was also completed in the pilot to ensure an efficient and organized data collection process, ready for analysis. As the instruments were self-administered instruments, inter-rater reliability did not need to be established.

Table 2: Text adaptations to questions in the self-efficacy measuring instruments

P-SEMI adaptations		
Item	**Original text**	**Adapted version text**
A2	I can maintain the established routine when my child protests.	I can maintain the established routine (e.g. bath time, getting dressed etc) when my child protests.
A4	I can create daily opportunities for conversation with my child.	I can create daily opportunities for conversation/communication with my child.
A7	I can spend time playing with my child.	I can easily spend time playing with my child.

A9	I can use daily routines to teach my child responsibilities.	I can use daily routines and activities to teach my child responsibilities.
A10	I can help my child to successfully complete daily routines.	I can help my child to successfully complete daily routines and activities.
A18	I can let my child know I still love him/her, after I have reprimanded him/her for misbehaving.	I can let my child know I still love him/her, after I have disciplined him/her for misbehaving.
A24	I can allow my child the freedom to make appropriate decisions independently.	I can allow my child the freedom to make appropriate decisions on their own.

PSOC adaptations		
Item	**Original text**	**Adapted version text**
B1	The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.	I understand how my actions affect my child which helps me to solve problems of taking care of my child.
B2	I meet my own personal expectations for expertise caring for my child.	I meet my own personal goals in caring for my child.
B3	I would make a fine model for a new parent to follow in order to learn what she would need to know to be a good parent.	I would be a good example to a new parent in order to learn what s/he would need to know to be a good parent.
B12	Sometimes I feel like I'm not getting anything done.	Sometimes I feel like I'm **not making any progress** with my child.

GSE adaptations		
Item	**Original text**	**Adapted version text**
C2	If someone opposes me, I can find the means and ways to get what I want.	If someone opposes me, I can find a way to get what I want.
C6	I can solve most problems, if I invest the necessary effort.	I can solve most problems, if I put in the necessary effort.

The instruments were translated into Afrikaans and isiXhosa by individuals who were fluent in English and Afrikaans or English and isiXhosa. The instrument was then back-translated into English, by different translators, to ensure reliability of the translation. This process was repeated when discrepancies were found. English and isiXhosa translations were printed together on the same combined form. Caregivers from the pilot study reported that even though their home language was isiXhosa they often could read English better than formal isiXhosa, as their colloquial language

makes use of many English words. Therefore, having both the English and isiXhosa translations together would give the caregiver the option to read either or both translations as preferred.

4.9 Data Collection

4.9.1 Data collection from assessments

The measuring instruments were administered to all caregivers enrolled in the study. The demographics questionnaire was administered at baseline. Self-efficacy measurements were obtained at baseline, at the midpoint of intervention (after 5 intervention sessions) and after the intervention period was complete (after a further 5 intervention sessions). Sessions occurred on a monthly basis. Data was collected at individual assessment appointments separate from the intervention sessions (when assessments for both caregivers and children were administered for all the parallel studies).

Although the instruments are primarily self-administered, assessors and translators were available at the time of completing the instrument to explain the assessment instructions. Prior to data collection, the researcher explained the assessments and requirements of administration to all assessors and translators involved in data collection. This included: how to explain the assessments and their purpose; instructions to complete the questionnaires; giving a choice of preferred language and translator options; explaining to caregivers that all questions need to be filled in and that the assessor needs to check afterwards that all questions were answered; encouraging the caregiver to respond honestly to how they currently feel at the time and not what they desire to feel; encouraging caregivers to ask questions if they are unsure; and, explaining to caregivers that the forms are kept anonymous and labelled with a code for the research team. This explanation was accompanied with a hard copy memorandum (Appendix H: Self-efficacy measuring instruments administration memo) that was kept with the assessment for the assessors to refer to as well as an electronic version that was emailed for the assessors to go through in preparation of the data collection. The researcher was also available to be contacted if there were any queries.

4.9.2 Data collection from interventions

Intervention attendance was tracked throughout the intervention period by the experimental and control intervention therapists.

The intervention therapist administering conventional occupational therapy to the control group recorded attendance on an attendance register. These details included attendance of the child and the caregiver. As a pragmatic study, the conventional intervention followed an approach of what would usually happen in the clinic context (Alford, 2007). In this context, some children attend their usual clinic appointments with different caregivers depending on which caregiver is available at the time. Some caregivers also have their own doctor appointments to attend on the same days as their children's appointments and/or go to the pharmacy while their children are being seen by a therapist. Thus, they were not always able to attend the intervention session. Additionally, as this type of intervention was more about the OT working directly with the child, the OT did not emphasise consistent attendance to the caregivers (contrary to caregivers partaking in PICIHBI). Therefore, the details recorded from the conventional therapy register included which caregiver attended the session (i.e. the designated caregiver participant or another caregiver) and whether they attended the session for the full/most duration, part of the session or none of the session.

The intervention therapist administering PICIHBI for the experimental group (who is also the researcher of this study) also recorded attendance on a register. The intervention therapist emphasised to the participants that the intervention was primarily for the caregivers and were encouraged to keep consistent in their attendance as the main participants in this type of intervention. When there were times where a different caregiver accompanied child when the primary caregiver participant could not attend, the new caregiver and child were still afforded the opportunity to attend PICIHBI but the primary caregiver participant was recorded as absent.

For this study, the particular data collection of interest for analysis was the attendance of designated caregiver study participant for both the control and experimental groups.

4.9.3 Data management

Once an individual assessment was complete the assessor immediately placed the hard copy data into a secure data box which was stored in a locked office space at the clinic. The researcher also created a data tracking spreadsheet to manage the data collected at each assessment period. When the data was not being used the box was always kept locked. Data was captured into data

programmes that were password protected. A co-researcher helped to ensure accuracy of data collection by double checking entries were captured correctly into the programme. Hard copies were destroyed after data was captured.

4.10 Data Analysis Procedure

The researcher conducted all analyses and consulted with a statistician to confirm that analysis procedure was appropriate with the characteristics of the data and results.

Raw data was initially captured into Microsoft excel spreadsheets and then exported to SPSS Statistics (IBM Corp., 2016) for analysis. As all the measures represented a 6-point Likert scale with point 1 representing high self-efficacy and point 6 representing low self-efficacy, the scores were reversed in SPSS Statistics so that the higher rank would correspond to higher self-efficacy. However, the 9 PSOC items that were reverse scored in the questionnaire were not reversed again in this process so that there was consistency in numerical association of high and low self-efficacy scores across all items and measures.

Initial analyses were conducted to verify the validity of the results. The distribution of data was analysed. Cronbach alpha coefficients were used to determine internal consistency performed on the baseline results for the scales and subscales of the outcome measure. Chi-square tests were used to test for associations between groups to ensure there was no significant difference between the groups relating to demographic variables at baseline. Available case analysis was followed to analyse the outcome measures over time of caregivers that completed assessments at all three time points regardless of how many intervention sessions were attended (Higgins & Green, 2008). Missing values in data from the available cases was calculated and analysed. The mean age of caregivers per group were determined using an independent *t*-test. Other demographic details of the sample were recorded per group with descriptive analysis and represented by frequency tables. The ordinal data from the self-efficacy instruments was compared using Mann-Whitney (Wilcoxon rank-sum) test. The Friedman test determined if there was a significant difference between time points within group and post hoc analysis with Bonferroni's correction applied determined between which time points the difference was. For all data analysis, a significance level of $p < .05$ was utilized, excluding when Bonferonni's correction was applied and significance level was $p < .017$.

4.11 Ethical Considerations

The Human Research Ethics Committee (HREC) at the Faculty of Health Sciences, University of Cape Town, granted ethical approval for this study (HREC ref 084/2015). This study is nested within a larger research study which was also granted ethical approval (HREC ref 560/2013). Refer to Appendix C: Ethical approval for the ethical approval letters and renewal.

There were no adverse effects involved in the assessment or intervention of this study. However, participation in the study requires the participant's time for assessment and intervention. A caregiver was required approximately 45 minutes to complete the adapted P-SEMI, PSOC and GSE, thus a total of 135 minutes over the study period was required for assessment for this study. Time required for all assessments across parallel studies, including this study, was 6 hours over the duration of the study period. For participants in the control group, a time requirement of 45 minutes contact time on a monthly basis for 10 sessions was needed whilst their children received conventional intervention. Participants in the experimental group needed to attend a 1.5 hour group intervention session for 10 monthly sessions.

The following ethical considerations were explained explicitly to the caregivers at recruitment. These factors were also stated in the information letter given to the caregivers and also on the consent form which they signed to agree to be part of the study (Appendix E: Information letters and consent forms).

4.11.1 Autonomy

Participants had the choice to participate and withdraw at any stage throughout the research process. Information letters with details of the study were given to the caregivers to keep at recruitment so that they could go back to check details later should they have wished to do so (Appendix E: Information letters and consent forms). In addition to parent consent, children that were 7 years of age at time of recruitment signed their names to give their assent to participate in

the study. Although the caregivers were the participants assessed in this study, the intervention process involved the children's participation and thus, required their assent.

4.11.2 Beneficence

Research and intervention appointments were made with the caregivers in mind to be as convenient as possible. Research and intervention appointments were scheduled with clinic appointments, where possible, to avoid the caregivers making an extra trip to the site. The caregivers were given all their intervention appointments ahead of time on their clinic card so that they could plan their time. Not all children had monthly clinic appointments with the doctor, however, during months when children did not have a doctor's appointment, caregivers still had to make a trip to collect medication at the hospital pharmacy. The researcher made contact with pharmacy staff to make them aware of the research and that caregivers could ask for a pharmacy appointment date on the same day as intervention. The staff were in support of the research and agreed to collaborate with making pharmacy appointments. The caregivers were then encouraged to liaise with pharmacy to book their following pharmacy appointment on the same day as the intervention. This was another strategy to avoid the caregivers making an additional trip to GSH.

Both types of interventions were of benefit to the caregiver-child dyad to enhance the child's development, learning and play, however, the interventions made use of different strategies. The conventional occupational therapy targeted the individual child's specific occupational needs to enhance their performance. PICIHBI aimed to provide skills to assist and empower the caregivers to address their children's specific needs. There was no occupational therapy service provided at the clinic external to the research study at the time intervention commenced, and therefore, the study provided an additional service opportunity for the caregiver-child dyad.

If another caregiver attended the clinic who was not the designated caregiver for the study, the caregiver and child were still offered the opportunity to benefit from the allocated intervention, however, this was not included in the analysis of the participant's attendance.

4.11.3 Non-maleficence

The research has had no adverse effects. The HIV-status of the participants was kept confidential within the clinic and research team. Written forms of communication for the caregivers were put in sealed envelopes and given to them directly from a researcher or a clinic staff member. Letters of absenteeism sent to school teachers and to caregiver employees did not disclose the child's status and did not display the "Kidzpositive" logo with its HIV association. When a caregiver needed to be contacted telephonically and the initial contact on the telephone was someone other than the caregiver, there was no mention of anything that disclosed the child's status.

Kidzpositive Family Fund provided R20 financial assistance to the caregivers and children to help cover some of the transport costs when there was a booking for the doctor. When caregivers and children attended a research assessment or intervention appointment without having a doctor's appointment, they were subsidized with the same monetary amount for transport from the research budget. Caregivers and children, who travelled long distances that required higher transport costs, were not expected to spend extra money to attend research or intervention appointments. Caregivers were made aware that should they decide not to be part of the study or withdraw that there would be no negative consequences held against them and they could continue with their usual clinic services. This was also stated in the information and consent letter.

4.11.4 Confidentiality

Privacy and confidentiality were upheld as no names were used when capturing and analysing the data. The caregivers and children received participant codes which were used throughout the study. There was only one document with the participant codes and names in the same document. The coding document with codes and names was stored in a password protected file on the researcher's computer and could only be accessed by researchers. Decoding of participants was used only for individual feedback of assessment results to caregivers and for the intervention therapist to be informed of relevant details for intervention purposes. No names have been or will be, revealed in research write-ups or published documents.

4.11.5 Justice

Participants were randomly allocated into control and experimental groups and were not given preference to either of the treatments. Participants in PICIHBI were given a stimulation box and toys throughout the intervention period as part of the intervention programme. Participants in the control group received the stimulation box with all the same toys at the end of the intervention period as this did not form part of the conventional therapy. All participants received the same amount of transport money which is comparable with the same amount that Kidzpositive administers at the clinic for regular clinic appointments to all their patients.

4.11.6 Referrals

During research data collection and intervention, psychosocial challenges, requiring special attention, arose in interacting with caregivers or children. In these instances, the participants were referred to their respective counsellors at the clinic. The clinic social worker and psychologist were also available for referral when greater expertise was needed for particular cases. A referral system was also put in place for children that were found to require additional support or services.

5 Results

5.1 Introduction to results

This chapter describes the results of the study. A flow diagram accompanies the description of recruitment and attrition. Demographics of the caregiver and child participants are presented. Following initial analysis to investigate the nature and integrity of the data, baseline data and repeated measure results are analysed within and between the groups.

5.2 Recruitment and Attrition

5.2.1 Consort Flow Diagram

Please refer to the consort diagram in Figure 2 for a diagrammatic representation of enrolment, allocation, intervention, assessment at different time points and analysis of the study.

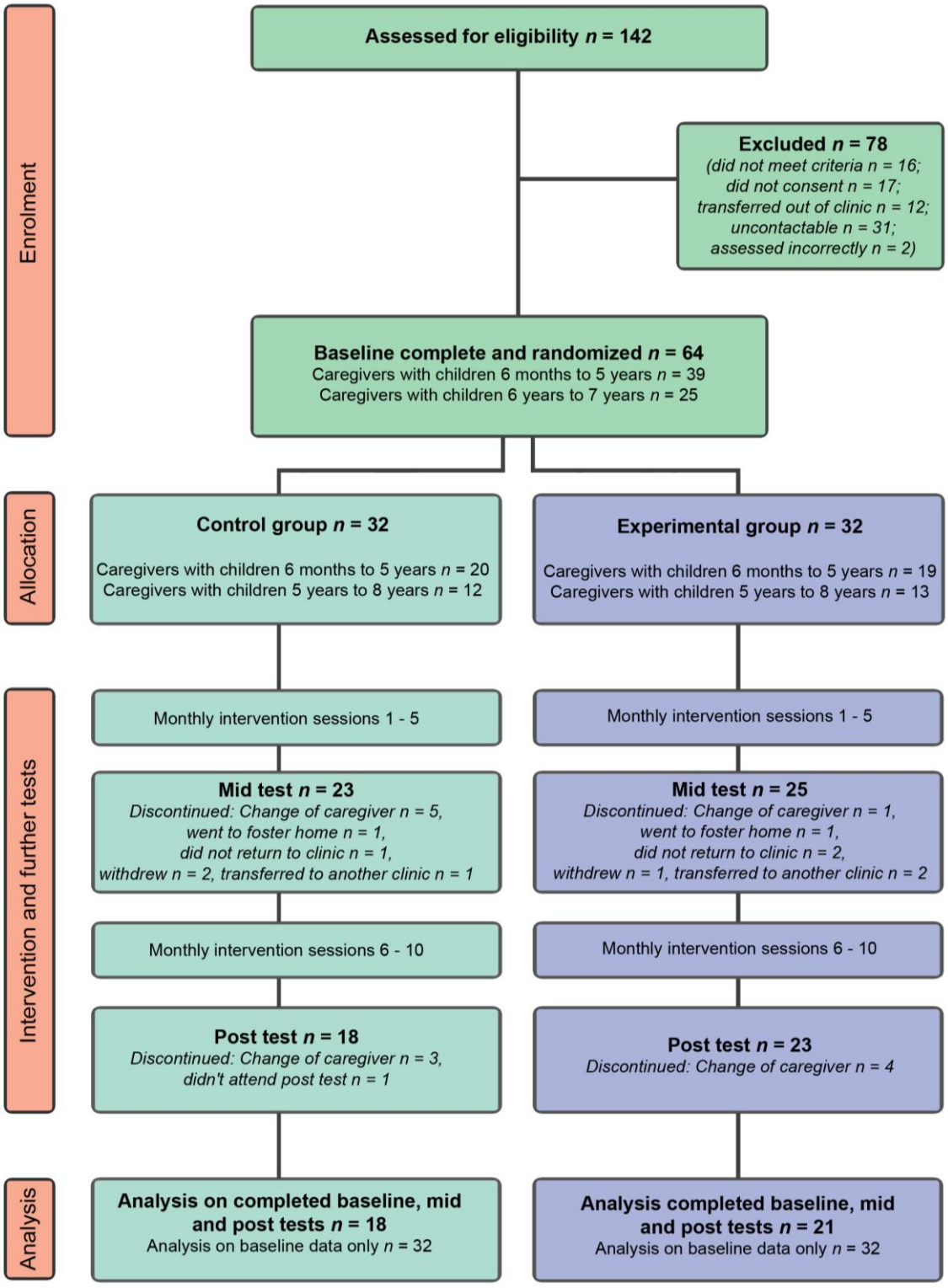


Figure 2: Study and participant flow diagram

5.2.2 Enrolment

On the clinic database there was a population of 142 children born between January 2007 and June 2013. The process of enrolment posed a few pragmatic challenges:

- Some of the clinic data had not been updated which resulted in patients who had been transferred out to another clinic or were no longer attending clinic services still being recorded on the clinic data sheet. Therefore, the initial population number of patients attending the clinic at the time of recruitment was incorrect.
- Contact details were out of date. From experience of working with the caregivers in the context, the researcher noted that caregivers' contact details would often change but the updates on the administrative systems utilised by the clinic were frequently not changed frequently.
- Many caregivers did not have a voice messaging system on their cellular phones and recruiters could not leave voice messages inviting the caregivers to participate in the study.

Of the 142 caregiver-child dyads, 64 caregivers gave consent and were enrolled into the study. The breakdown of the reasons for the 78 child-caregiver dyads who were not enrolled into the study were as follows:

- Caregiver-child dyads did not meet criteria (*n* = 16).
- Caregivers did not give consent due to time and transport limitations (*n* = 17).
- Caregiver-child dyads (*n* = 2) were assessed but marked incorrectly by assessors. This meant that the researcher could not identify and connect the demographics and various self-efficacy assessments to the correct participant.
- Children were still displayed on the active patient records but had been transferred out to another clinic (*n* = 12).
- Caregiver-child dyads were uncontactable during the 3 months recruitment period (*n* = 31) where clinic appointments were missed, and contact details were invalid or missing from medical files.

The two participant dyads who gave consent and completed baseline assessment and whose assessments were incorrectly marked by the assessors, were still offered intervention throughout the study period but their results were not included in the data analysis.

5.2.3 Attrition and numbers analysed

Sixty-four participants completed baseline assessments and were randomised (32 in the experimental group and 32 in the control group). Thirty-nine (*n* = 39) of these participants completed all the assessments at the three data collection points. Thus, analysis of data over all three time points was conducted with 39 participants. The remaining 25 caregivers discontinued or did not complete assessments at all three time points for the following reasons:

- Changeover of primary caregiver (*n* = 13) tending to clinic activities during data collection due to change in social circumstances or death
- Child (*n* = 2) went into foster care
- Caregiver and child (*n* = 1) did not attend assessment appointments after numerous attempts to contact and reschedule appointments
- Caregiver and child (*n* = 3) did not return to clinic and could not be contacted through the remainder of the study period
- Caregiver (*n* = 3) withdrew from study for own reasons
- Caregiver and child (*n* = 3) were transferred to another clinic facility

This indicates some of the practical challenges to implementing caregiver interventions in the public health care sector.

5.3 Demographic details

Sixty-four caregivers were enrolled into the study of which 61 (95%) were female and 3 (5%) were male. The mean age for the caregivers was 34,87 years with a standard deviation of 11,89 years and a range of 22 to 72 years. The majority of the participants were the biological mother of the child (*n* = 48, 75%), spoke isiXhosa as their first language (*n* = 52, 81%), had completed at least grade 10 level education (*n* = 45, 70%), were unemployed (*n* = 50, 78%) and had less that R1600 total household monthly income (*n* = 39, 61%). Typically, the child enrolled in the study was not the caregiver's first child (*n* = 44, 69%).

Levene's test for equality of variances showed homogeneity of variance in caregiver age ($F < .000$, $p = .996$) for the two groups. An independent-samples *t* test proved that there was no statistical significance between caregiver age and group, $t(59) = -.365$, $p = .72$, 95% CI [-7.26, 5.02]. Pearson Chi-square analyses also demonstrated that there was no statistical difference between group and

the remaining categorical variables at baseline (the χ^2, df and *p*-values are indicated in Table 3 below).

Table 3: Caregiver sample demographic results

	Control Group *n* = 32	Experimental Group *n* = 32	Total *N* = 64	Difference (df)	*p*
Gender					
Male	2 (6%)	1 (3%)	3 (5%)	χ^2 = .35 (1)	.55
Female	30 (94%)	31 (97%)	61 (95%)		
Age					
Mean	35.42 (11.36 SD)	34.30 (12.58 SD)	34.87 (11.89 SD)	*t* = -.37 (59)	.72
Range	23 – 69	22 – 72	22 - 72		
Relationship to child					
Biological mother	23 (72%)	25 (78%)	48 (75%)	χ^2 = 4.43 (6)	.62
Biological father	1 (3%)	0 (0%)	1 (2%)		
Sister	0 (0%)	1 (3%)	1 (2%)		
Grandmother	4 (13%)	3 (9%)	7 (11%)		
Aunt	2 (6%)	3 (9%)	5 (8%)		
Foster parent (female)	1 (3%)	0 (0%)	1 (2%)		
Foster parent (male)	1 (3%)	0 (0%)	1 (2%)		
Home language					
Xhosa	26 (81%)	26 (81%)	52 (81%)	χ^2 = 4.20 (3)	.24
English	3 (9%)	0 (0%)	3 (5%)		
Afrikaans	2 (6%)	3 (9%)	5 (8%)		
Other	1 (3%)	3 (9%)	4 (6%)		
Level of education					
Less than grade 9	7 (22%)	8 (25%)	15 (23%)	χ^2 = 1.38 (5)	.93
Grade 9	2 (6%)	2 (6%)	4 (6%)		
Grade 10	6 (19%)	5 (16%)	11 (17%)		
Grade 11	6 (19%)	6 (19%)	12 (19%)		
Grade 12	10 (31%)	8 (25%)	18 (28%)		
Postsecondary education	1 (3%)	3 (9%)	4 (6%)		
Employment					
Unemployed (at baseline)	25 (78%)	25 (78%)	50 (78%)	χ^2 = 0.00 (1)	1
Employed (at baseline)	7 (22%)	7 (22%)	14 (22%)		
Total household income per month					
Below R1 600	21 (66%)	18 (56%)	39 (61%)	χ^2 = 0.59 (2)	.74
R1 600 - R3 200	7 (22%)	9 (28%)	16 (25%)		

Above R3 200	4 (13%)	5 (16%)	9 (14%)		
Number of children in household to look after					
1 child	5 (16%)	9 (28%)	14 (22%)	χ^2 = 1.16 (1)	.28
2-3 children	22 (69%)	19 (59%)	41 (64%)		
4 or more children	4 (13%)	4 (13%)	8 (13%)		
Adult support in household					
No other adult support	5 (16%)	7 (23%)	12 (20%)	χ^2 = 0.50 (1)	.48
Other adults in household	26 (84%)	23 (77%)	49 (80%)		

This study primarily focussed on the caregivers, however, the children were also involved in the interventions and child characteristics can also influence CSE (Roskam & Meunier, 2012). Consequently, key child characteristics were explored at baseline to establish equivalence between the two groups. Homogeneity of variance in child age was established with Levene's test for equality of variances (F = 2.712, p = 0.105). The mean age of children in the study was 54.89 months with a standard deviation of 21.16 months. Schooling, and time on ART were also equivalent between the two groups. Please see Table 4 for these results.

Table 4: Child sample demographic results

	Control Group *n* = 32	**Experimental Group *n* = 32**	**Total *N* = 64**	**Difference (df)**	***p***
Child age at baseline					
Mean age in months	57.34 (SD=11)	52.44 (SD=13)	54.89 (SD=21.16)	*t*= -0.93 (62)	.358
Range in months	10 - 83	5 - 84	5 - 84		
Gestation					
Born premature (≤36 weeks)	7 (23%)	8 (26%)	15 (25%)	χ^2 =1.27 (2)	.53
Born at term (≥37 weeks)	23 (77%)	23 (74%)	46 (75%)		
Other diagnoses and complications in addition to HIV					
TB History	11 (34%)	9 (28%)	20 (31%)	χ^2 = 0.59 (2)	.746
Additional neurological or developmental conditions (including: failure to thrive, meningitis, microcephaly, developmental delay, cerebral palsy, and epilepsy)	5 (16%)	9 (28%)	14 (22%)	χ^2 = 1.46 (1)	.226
Schooling					
Not attending any school	7 (22%)	11 (34%)	18 (28%)	χ^2 = 4.89 (4)	.299
Attending nursery school	15 (47%)	10 (31%)	25 (39%)		
Grade R	3 (9%)	7 (22%)	10 (16%)		

Grade 1	6 (19%)	4 (13%)	10 (16%)		
Grade 2	1 (3%)	0 (0%)	1 (2%)		
Child's primary playmate					
Caregiver is main playmate	2 (6%)	6 (19%)	8 (13%)	$\chi^2 = 2.29$ (1)	.131
Child has another primary playmate	30 (94%)	26 (81%)	56 (88%)		
Time on ART					
< 1 year	3 (10%)	3 (9%)	6 (10%)	$\chi^2 = 5.21$ (7)	.635
1 year	3 (10%)	6 (19%)	9 (14%)		
2 years	4 (13%)	2 (6%)	6 (10%)		
3 years	4 (13%)	8 (25%)	12 (19%)		
4 years	4 (13%)	5 (16%)	9 (14%)		
5 years	6 (19%)	2 (6%)	8 (13%)		
6 years	5 (16%)	4 (13%)	9 (14%)		
7 years	2 (7%)	2 (6%)	4 (6%)		

These results indicate that the experimental and control groups were comparable on key caregiver and child characteristics at baseline.

5.4 Baseline Data

5.4.1 Preliminary analysis of data integrity

Distribution of data was investigated with all scales at baseline using the Shapiro-Wilk test. All data was found to not be distributed normally ($p < .05$). Therefore, non-parametric analyses were used for further analysis.

Despite the protocol for assessors to check that all items across the measures were completed by the caregiver, some missing data ensued. Knowing that analysing a complete data set with predicted values would be more powerful than analysing an incomplete data set, the option of imputation was explored (Cheema, 2014). Missing value analysis was conducted in SPSS and determined that 2.99% of the data was missing at baseline for the whole sample ($N = 64$) and 2.64% of the data was missing across all three scales and time points in the sample ($N = 39$) who completed assessments at all three time points. Little's test of missing completely at random (1988) resulted in χ^2 (7726, $N = 64$) = 1888.27, $p = 1.00$ for baseline results and χ^2 (2106, $N = 39$) = 2781.99, $p = 1.00$ for results from the sample analysed across the three time points. This indicated that the data was missing completely at

random and could be imputed using the Expectation Maximization algorithm, following imputation guidelines outlined by Cheema (2014).

Scale reliability and internal consistency analyses were conducted on the total scales and subscales of all 3 measures using the Cronbach alpha coefficient on the total sample (*N* = 64) with baseline data. The P-SEMI and GSE scales demonstrated good total scale reliability with Cronbach alpha coefficients above .70 (α = .93 and α = .78 respectively) and the total PSOC scale demonstrated adequate internal consistency with a Cronbach alpha coefficient of .66 (Nunnally & Bernstein, 1994). The internal consistency for the total P-SEMI scale was high (α = .93), however, it is noted that long scales with over 20 items will likely give high alpha scores (Hair, Black, Babin, Anderson, & Tatham, 2006; Streiner, 2003). The alpha values of each subscale were investigated along with the inter-item and item total correlations and how the items affected the reliability of the subscale if deleted. Nine of the 70 items across all three scales that had low item-total correlations and that would also give a higher subscale alpha value if deleted from the scale, were removed. All further statistical analyses were completed with these items removed. For a breakdown of the initial item-total correlations and subscale internal consistency for all measures refer to Appendix J: Item-total correlations and Cronbach alpha reliability coefficients for P-SEMI and PSOC subscales and GSE scale. The summary of the alpha values of the subscales, before and after items were removed, are shown in Table 5. The majority of the adjusted subscales (on all 3 of the measures) had an internal consistency of greater than 0.7 and thus could be used reliably for further analysis (Hair et al., 2006). The PSOC scale and two P-SEMI subscales (engaging in play, and, showing affection and empathy) had adjusted alpha values of .67, .67 and .64 respectively, which, remained below the suggested 0.7 cut-off score, however, these values are still acceptable for exploratory research (Hair et al., 2006).

Table 5: Cronbach Alpha values per scale/subscale before and after removing items with low correlation and that lower the alpha value

Scale/subscales (*n* = number of valid cases analysed)	**Initial α**	**Item number removed**	**Number of items in subscale**	**Revised α**
P-SEMI total scale (*n* = 43)	.93	P-SEMI items 3, 22, 24, 34, 35	38	.92
P-SEMI subscale:				
Establishing discipline strategies (*n* = 61)	.73	None	8	.73

Facilitating routines (*n* = 59)	.62	P-SEMI item 34	6	.75
Engaging in play (*n* = 56)	.61	P-SEMI items 3, 35	5	.67
Promoting communication interaction (*n* = 56)	.74	None	7	.74
Showing affection and empathy (*n* = 57)	.64	None	7	.64
Providing appropriate activities for learning and development (*n* = 58)	.69	P-SEMI items 22, 24	5	.74
PSOC total scale (*n* = 49)	.66	PSOC items 6, 11, 17	14	.67
PSOC satisfaction subscale (*n* = 54)	.79	PSOC item 6, 17	7	.84
PSOC efficacy subscale (*n* = 56)	.52	PSOC item 11	7	.71
GSE total scale (*n* = 56)	.78	GSE items 2, 6	8	.81

5.4.2 Baseline data for caregiver and general self-efficacy

Scale and subscale baseline scores, were summed per case (*N* = 64) and compared using Mann-Whitney-U to determine if there was a difference between the two groups at baseline. The Mann-Whitney-U analysis revealed that the groups were not significantly ($p > .05$) different from each other at baseline for any of the scales or subscales. Refer to Table 6 for the detailed baseline self-efficacy results. Table 7 describes the ranked order of the P-SEMI subscales from low to high CSE at baseline with each group. Some controversy exists relating to the PSOC and using the total scale for the construct of parental efficacy as some studies found that the subscales were highly correlated (Bor & Sanders, 2004; Caldwell, Shaver, Li, & Minzenberg, 2011; Knoche, Givens, & Sheridan, 2007; Ohan, Leung, & Johnston, 2000). However, Spearman's rho conducted on the PSOC subscales from the data in this study indicate a negligible correlation r_s (64) = .187, p = .138, *ns* (Hinkle, Wiersma, & Jurs, 2003). Thus, it was decided to analyse these subsections separately. A Wilcoxon Signed-Rank Test conducted on the total sample (*N* = 64) at baseline indicated that the parental satisfaction subscale (*M* = 3.12, *SD* = 1.20) was significantly lower than the mean of the parental efficacy subscale (*M* = 5.28, *SD* = .65) *Z* = -6.137, $p < .001$, further supporting the decision to retain the two subscales in subsequent analyses.

Table 6: Baseline self-efficacy results per group

	Experimental Group (N = 32)				Control Group (*N* = 32)				Mann-Whitney-U	
	Case *M*	Sum value *M*	*SD*	Case range	Case *M*	Sum value *M*	*SD*	Case range	*U*	*p*
P-SEMI total scale	5.17	196.55	21.94	161-228	5.16	196.18	23.72	131-228	506.5	.94
Establishing discipline strategies	4.66	37.31	7.20	23-48	4.64	37.15	7.50	17-48	504.5	.92
Facilitating routines	5.08	30.47	5.03	20-36	5.34	32.05	4.25	20-36	417.5	.20
Engaging in play	5.28	26.41	3.70	18-30	5.29	26.43	3.43	16-30	486.0	.73
Promoting communication interaction	5.37	37.56	4.55	27-42	5.19	36.31	5.14	23-42	435.0	.30
Showing affection and empathy	5.57	38.97	3.20	33-42	5.45	38.15	4.49	28-42	476.5	.63
Providing appropriate activities for learning and development	5.17	25.84	3.96	17-30	5.22	26.09	3.98	16-30	485.5	.72
PSOC total scale	4.23	59.19	6.68	47-70	4.07	56.96	9.13	43-77	409.5	.17
PSOC efficacy subscale	5.21	36.49	4.38	22-42	5.14	35.98	5.04	20-42	496.5	.84
PSOC satisfaction subscale	3.24	22.69	7.51	7-42	3.00	20.98	9.19	7-40	438.5	.32
GSE total scale	4.95	39.59	6.27	21-48	5.27	42.13	4.26	32-48	391.0	.10

M = Mean; SD = Standard deviation

Table 7: Ranking of P-SEMI subscales from low to high CSE at baseline per group

Rank (low to high CSE)	Experimental group	Control group
1	Establishing discipline strategies	Establishing discipline strategies
2	Facilitating routines	Promoting communication interaction
3	Providing appropriate activities for learning and development	Providing appropriate activities for learning and development
4	Engaging in play	Engaging in play
5	Promoting communication interaction	Facilitating routines
6	Showing affection and empathy	Showing affection and empathy

5.5 Repeated measure results over the study period

Means of the summed scores (over the three time points) for each scale and subscale were computed for both groups (experimental group n = 21, control group n = 18). Friedman's test was used to determine whether there was significant change over time within each group per subscale. Post hoc analysis using the Wilcoxon signed-rank test was conducted with subscales that demonstrated significant change to determine where the difference lay i.e. between which time points. Bonferroni's correction was applied with a significance level set at $p < .017$ for post hoc analysis. Effect sizes were calculated using the Z-scores divided by the number of observations ($r = Z / \sqrt{N}$).

5.5.1 The P-SEMI scores over time *within* each group

The Friedman test, which evaluated the difference between the means among the three time periods, indicated significant change in the P-SEMI total scale for both the experimental group $\chi^2(2, N = 21) = 18.286$, $p < .001$ and the control group $\chi^2(2, N = 18) = 15.577$, $p < .001$. Kendall's W is .44 for the experimental group and .43 for the control group indicating a moderate agreement among raters and thus a fairly strong difference between the three timepoints (Landis & Koch, 1977). The

mean P-SEMI scores for the experimental group were 198.51 (*SD* = 21.06) at baseline, 164.79 (*SD* = 19.37) at mid-test and 196.24 (*SD* = 27.61) at post-test. The mean P-SEMI scores for the control group were 197.27 (*SD* = 25.61) at baseline, 161.32 (*SD* = 24.18) at mid- test, and 195.78 (*SD* = 25.67) at post-test. The post hoc analysis with Wilcoxon signed-rank test and Bonferroni correction applied indicated that there was a significant difference with moderate effect sizes between both baseline and mid-test (z = -3.91, p < .001, r = - .603), as well as between mid-test and post-test (z = -3.70, p < .001, r = - .571) for the experimental group (Cohen, 1988). Similarly, the control group also demonstrated significant difference and moderate effect sizes between baseline and mid- test (z = -3.101, p = 0.002, r = - .517) and mid-test and post-test (z = -3.092, p = 0.002, r = - .515) (Cohen, 1988). However, post hoc analysis between baseline and post-test indicated that there was not a significant difference between these two points for both experimental and control group (z = -1.39, p = 0.889 and z = -3.7, p = .711 respectively). Table 8 presents the results from the Friedman test for the P-SEMI subscales. There was no significant difference (p > .05) in the change over time for any of the P-SEMI subscales. In summary, significant differences were found on P-SEMI total scale where there was a decrease from baseline to mid-test and an increase from mid-test to post-test in both groups.

Table 8: Friedman's test analysing P-SEMI and subscales change over time

	Experimental group (*N* = 21)								Control group (*N* = 18)							
	Baseline		Mid- test		Post-test		χ^2 (df)	*p*	Baseline		Mid- test		Post-test		χ^2 (df)	*p*
	Sum *M* (*SD*)	Case *M*	Sum *M* (*SD*)	Case *M*	Sum *M* (*SD*)	Case *M*			Sum *M* (*SD*)	Case *M*	Sum *M* (*SD*)	Case *M*	Sum *M* (*SD*)	Case *M*		
P-SEMI total	198.51 (21.06)	5.22	164.79 (19.37)	5.22	196.24 (27.61)	5.16	18.29 (2)	<.00	197.27 (25.61)	5.19	161.32 (24.18)	5.11	195.78 (25.67)	5.15	15.58 (2)	<.00
Disc.	39.06 (6.23)	4.88	38.94 (6.93)	4.87	38.07 (8.22)	4.76	.03 (2)	.99	37.10 (8.83)	4.64	39.49 (6.34)	4.94	39.44 (5.47)	4.93	1.49 (2)	.48
Rout.	30.68 (4.91)	5.11	31.13 (4.33)	5.19	29.89 (6.21)	4.98	.32 (2)	.85	32.42 (4.45)	5.40	30.67 (4.51)	5.11	31.41 (3.79)	5.23	.74 (2)	.69
Play	26.47 (3.77)	5.29	26.56 (3.76)	5.31	27.29 (3.12)	5.46	2.60 (2)	.27	26.50 (4.04)	5.30	25.33 (5.08)	5.07	25.66 (4.88)	5.13	1.39 (2)	.50
Comm.	37.69 (4.42)	5.38	36.49 (5.31)	5.21	36.78 (5.62)	5.25	1.64 (2)	.44	36.26 (5.00)	5.18	36.10 (4.33)	5.16	36.12 (5.56)	5.16	.90 (2)	.64
Affec.	38.87 (3.40)	5.55	38.58 (4.78)	5.51	37.19 (5.80)	5.31	2.76 (2)	.25	38.37 (4.61)	5.48	37.19 (5.60)	5.31	37.63 (5.15)	5.38	.84 (2)	.66
Learn	25.75 (4.09)	5.15	26.64 (3.02)	5.33	27.01 (3.17)	5.40	1.83 (2)	.40	26.62 (3.93)	5.32	25.23 (5.04)	5.05	25.52 (4.06)	5.10	.41 (2)	.82

Disc. = Establishing discipline strategies, Rout. = Facilitating routines, Play = Engaging in play, Comm. = Promoting communication interaction, Affec. = Showing affection and empathy, Learn = Providing appropriate activities for learning and development

5.5.2 The PSOC and GSE scores over time *within* each group

Table 9 presents results from the Friedman's test conducted on the PSOC, PSOC subscales and GSE for each group. The table indicates no significant changes between the repeated measures of the PSOC total scale and subscales over time with all *p*-values > .05. A similar pattern to the P-SEMI is reflected in the PSOC total scale and efficacy subscale with a slight decline from baseline and rise in CSE from mid-test, in both groups. The satisfaction subscale displayed opposing patterns between groups, although there were not significant changes. The experimental group decreased over the time points and the control group increased over the time points. There was also no significant change with repeated measures for both the experimental and control groups in the GSE scale with a *p* value of .55 and .34 respectively from the Friedman's test. Although the change was not significantly different, the pattern displayed in the GSE depicted a slight increase and then decrease in the experimental group and the opposite pattern with a slight decrease and then increase in the control group.

Table 9: Friedman's test analysing PSOC, PSOC subscales and GSE change over time

	Experimental group (*N* = 21)					Control group (*N* = 18)				
	Baseline Mean (*SD*)	**Mid-test mean (*SD*)**	**Post-test mean (*SD*)**	**χ^2 (df)**	***p***	**Baseline Mean (*SD*)**	**Mid-test mean (*SD*)**	**Post-test mean (*SD*)**	**χ^2 (df)**	***p***
PSOC total scale	59.00 (7.21)	57.13 (7.75)	56.89 (8.59)	1.951 (2)	.38	56.21 (9.90)	55.09 (8.22)	57.56 (7.94)	.57 (2)	.75
PSOC efficacy subscale	36.82 (4.50)	35.48 (4.63)	35.65 (4.53)	2.395 (2)	.30	37.08 (4.79)	35.65 (4.85)	36.11 (6.32)	.26 (2)	.88
PSOC satisfaction subscale	22.18 (8.36)	21.65 (7.32)	21.24 (6.87)	.222 (2)	.90	19.14 (9.72)	19.43 (8.26)	21.45 (6.50)	2.56 (2)	.28
GSE scale	39.19 (6.68)	39.40 (5.01)	38.44 (5.29)	1.210 (2)	.55	43.56 (3.68)	40.30 (4.61)	42.50 (5.09)	2.15 (2)	.34

5.5.3 Analysis of caregiver and general self-efficacy scores *between* groups at different time points

Table 10 depicts the mean scores and standard deviations of both groups across all total scales and subscales, and for all test points for the analysed sample (*n* = 39). The difference between the groups at each test point was determined using the Mann-Whitney U test.

Table 10: Mean scores over time points and difference between groups for all scales for the analysed sample (*n*=39)

		Experimental	Control	Mann-Whitney U		
		Mean (*SD*)	Mean (*SD*)	*U*	*Z*	*p*
P-SEMI total scale	Baseline	198.51 (21.06)	197.27 (25.61)	183.0	-0.169	0.87
	Mid-test	164.79 (19.36)	161.32 24.18)	183.0	-0.169	0.87
	Post-test	196.24 (27.61)	195.78 (25.67)	174.0	-0.423	0.67
Establishing discipline strategies	Baseline	39.06 (6.23)	37.10 (8.83)	173.5	-0.439	0.66
	Mid-test	38.94 (6.93)	39.49 (6.34)	183.0	-0.169	0.87
	Post-test	38.07 (8.22)	39.44 (5.47)	178.0	-0.311	0.76
Facilitating routines	Baseline	30.68 (4.91)	32.42 (4.45)	148.5	-1.150	0.25
	Mid-test	31.13 (4.33)	30.67 (4.51)	181.5	-0.212	0.83
	Post-test	29.89 (6.21)	31.41 (3.79)	177.5	-0.326	0.74
Engaging in play	Baseline	26.47 (3.77)	26.50 (4.04)	180.5	-0.243	0.81
	Mid-test	26.56 (3.76)	25.33 (5.08)	169.0	-0.569	0.57
	Post-test	27.29 (3.12)	25.66 (4.88)	150.0	-1.125	0.26
Promoting communication interaction	Baseline	37.69 (4.41)	36.26 (4.96)	157.0	-0.907	0.36
	Mid-test	36.49 (5.30)	36.10 (4.33)	155.5	-0.948	0.34
	Post-test	36.78 (5.62)	36.12 (5.56)	167.0	-0.622	0.53
Showing affection and empathy	Baseline	38.87 (3.40)	38.37 (4.61)	185.5	-0.102	0.92
	Mid-test	38.58 (4.78)	37.19 (5.60)	142.0	-1.347	0.18
	Post-test	37.19 (5.80)	37.63 (5.14)	184.0	-0.142	0.89
Providing appropriate activities for learning and development	Baseline	25.75 (4.09)	26.62 (3.93)	158.0	-0.883	0.38
	Mid-test	26.64 (3.02)	25.23 (5.04)	178.5	-0.300	0.76
	Post-test	27.01 (3.17)	25.52 (4.06)	151.5	-1.066	0.29
PSOC total scale	Baseline	59.00 (7.21)	56.21 (9.90)	140.0	-1.383	0.17

	Mid-test	57.13 (7.75)	55.09 (8.22)	158.0	-0.874	0.38
	Post-test	56.89 (8.59)	57.56 (7.94)	178.0	-0.310	0.76
PSOC efficacy subscale	Baseline	36.82 (4.49)	37.08 (4.79)	171.5	-0.495	0.62
	Mid-test	35.48 (4.63)	35.65 (4.85)	188.0	-0.028	0.98
	Post-test	35.65 (4.53)	36.11 (6.32)	161.5	-0.780	0.44
PSOC satisfaction subscale	Baseline	22.18 (8.36)	19.14 (9.72)	145.0	-1.241	0.21
	Mid-test	21.65 (7.32)	19.43 (8.26)	150.5	-1.086	0.28
	Post-test	21.24 (6.87)	21.45 (6.49)	180.5	-0.240	0.81
GSE total scale	Baseline	39.19 (6.68)	43.56 (3.68)	108.0	-2.289	0.02
	Mid-test	39.40 (5.01)	40.30 (4.61)	183.5	-0.155	0.88
	Post-test	48.06 (6.70)	52.94 (6.00)	93.0	-2.711	0.01

The experimental group had slightly elevated CSE levels compared to the control group on the PSEMI domains of learning and play at the post intervention measure. However, the comparisons between the groups at different time points are not significant for any of the PSEMI or PSOC scales. There was a significant difference between the two groups for GSE (baseline and post-test). The control group possessed significantly higher levels of GSE at baseline and at the end of the intervention, compared to the intervention group. It is noted that there was no significant difference in the GSE between groups at baseline when comparing the total sample (*N = 64).*

5.6 Ancillary analyses

Ancillary analyses were conducted to illustrate the attendance of intervention between the groups as well as caregiver perception on their children's skills in learning, development and play.

5.6.1 Attendance

Table 11 displays how many sessions caregivers attended of the 10 sessions offered per group. It was noted that the attending caregiver would sometimes be different to the caregiver originally enrolled into the study for the corresponding child. For example, although the mother was enrolled into the study and explained that she was the participant to attend intervention, sometimes the grandmother would attend the clinic and intervention with the child due to unforeseen

circumstances. As the other adults were not enrolled into the study with the relevant assessments conducted, attendance details are only for the specific caregiver enrolled into the study within the analysed sample that completed all tests at the three time points (*n* = 39). Attendance was poor with the majority of participants attending less than half the sessions offered. Participants in the experimental group attended a sum total of 70 (33.33%) sessions of the potential 210 sessions with an average of each participant attending 3 sessions (*M* = 3.33, *SD* = 2.13). Participants in the control group attended a sum total of 60 (33.33%) sessions of the potential 180 sessions and also had an average of each participant attending 3 sessions (*M* = 3.33, *SD* = 2.40).

Table 11: Total number intervention sessions attended per group over the duration of the intervention period

Number of sessions attended	Analysed sample (*n* = 39)	
	Experimental Group	Control Group
0	0 (0%)	3 (17%)
1	5 (24%)	2 (11%)
2	4 (19%)	0 (0%)
3	5 (24%)	5 (28%)
4	0 (0%)	3 (17%)
5	2 (10%)	2 (11%)
6	4 (19%)	2 (11%)
7	0 (0%)	0 (0%)
8	1 (5%)	0 (0%)
9	0 (0%)	1 (6%)
10	0 (0%)	0 (0%)
Total	21	18

Table 12 displays caregiver attendance for each session in the different groups. Attendance for the first 5 sessions between baseline and mid assessment was higher than the attendance for the last 5 sessions between mid-test and post-test for both groups.

Table 12: Caregiver attendance per session and total session attendance

Session number	1	2	3	4	5	6	7	8	9	10	Total attendance (%)
Control group (*n* = 18)	10	7	6	2	6	6	5	10	5	3	60 (33.33%)
Experimental group (*n* = 21)	9	9	9	8	8	3	3	8	8	5	70 (33.33%)
Total sample (*n* = 39)	19	16	15	10	14	9	8	18	13	8	130 (33.33%)

For the experimental group, there was 40.95% attendance for sessions 1-5 and 25.71% attendance for sessions 6-10. The control group attendance was 34.44% for sessions 1-5 and 32.22% for sessions 6-10 and thus had less of a decrease in attendance than in the experimental group.

5.6.2 Caregiver perception on their child's development

Table 13 displays the results from the 5-point Likert scale investigating the caregivers' perceptions about their children's development, learning and play skills at baseline. It is evident that the majority of the caregivers thought that their children showed age appropriate or above average development, in both the experimental group (78.13%) and the control group (75.00%).

Table 13: Caregiver perception about the child's development, learning and play skills

Caregiver perception about child's development, learning and play	Control Group *N* = 32	Experimental Group *n* = 32	Total *N*=64	Difference (df)	*p*
Very concerned about development	3 (9.38%)	1 (3.23%)	4 (6.35%)	$\chi^2 = 1.30$ (4)	0.861
Developing a little slower than peers	6 (18.75%)	5 (16.13%)	11 (17.46%)		
Developing on par	20 (62.50%)	21 (67.74%)	41 (65.08%)		
Developing a little better	1 (3.13%)	1 (3.23%)	2 (3.17%)		
Developing very well for the child's age	2 (6.25%)	3 (9.68%)	5 (7.94%)		

5.7 Conclusion to results

Functional equivalence was demonstrated between the groups at baseline on key parent and child characteristics. Missing data was imputed using Expectation Maximization algorithm and data from 18 cases in the control group and 21 cases in the experimental group were retained for further analyses. Cronbach's alpha coefficients on the 3 scales and subscales indicated acceptable internal consistency for the measures in this study. Baseline results for both groups indicate high mean values for CSE on all scales and subscales. There were no significant differences within either group from baseline to post-test on any of the self-efficacy scales or subscales. However, there was a significant difference between baseline and mid-test, as well as between mid-test and post-test for both groups in the P-SEMI with CSE results decreasing to mid-test and then increasing to post-test. Attendance was poor with participants in both groups attending 33.33% of the sessions. Caregivers' perceptions of their children's development, learning and play showed that the majority of caregivers perceived their children to be on par (or better) than other children their age.

6 Discussion

6.1 Introduction to discussion

This chapter provides potential explanations for the CSE and general self-efficacy results at baseline and the significant changes between time points in the P-SEMI. The chapter continues with discussion on the changes in the P-SEMI subscales, PSOC and GSE as a result of the intervention. This is followed by discussing intervention attendance patterns, and caregivers' perceptions of their children's developmental capabilities.

There is a paucity of empirical data that explores changes in CSE in caregivers of HIV-positive children in any context, let alone South African studies using the same measuring instruments. Thus, various studies investigating CSE with at least one similar component to this research context were used to draw together meaningful interpretations of the results below. These studies include: studies measuring impact on CSE following parent training, studies using the same or similar measuring instruments, studies with families in a similar economic context, studies with vulnerable or at risk children, and studies embedded in a South African context.

6.2 Caregiver self-efficacy and general self-efficacy at baseline

At baseline, for both groups, the self-efficacy scales and subscales indicated that the average self-efficacy values were all above midpoint in the Likert scales. Similarly, a study conducted by Dorsey, Klein and Forehand (1999) investigating CSE in HIV-infected mothers, found that the levels of CSE were relatively high with a mean score of 86 on a 100-point scale. However, CSE was still significantly lower in HIV-infected mothers compared to uninfected mothers (Dorsey, Klein & Forehand, 1999). When comparing the evidence to this study, the caregivers in this study are not necessarily HIV-infected mothers. However, 75% of the sample are biological mothers of their HIV-positive children, suggesting that the vast majority are HIV-infected mothers. The evidence infers that, despite high baseline scores of CSE in the sample, these could still be considerably lower than caregivers in non-affected HIV families. However, an equivalent caregiver group not affected by HIV was not measured

and thus, conclusive evidence that CSE is lower in HIV-affected caregivers in this population cannot be explicitly stated, limiting the viability of the study and intervention.

Although no published studies could be found that have used the P-SEMI, an unpublished dissertation by Williamson (2016) used the P-SEMI to measure CSE of mothers of children with ADHD. The mean score for the P-SEMI total scale was 4.85 (*SD* = .78) which is lower than the means of this study (*M* = 5.17 for the experimental group and *M* = 5.16 for the control group) (Williamson, 2016). P-SEMI subscale scores from the study were not reported. Considering the Williamson (2016) study results in comparison to this study, with further research it could suggest that CSE could be higher in caregivers with HIV-positive children compared to caregivers of ADHD children. However, mothers in the Williamson (2016) study were typically married, employed, had some education from a tertiary institute and were not in the low income bracket, and thus different in some key aspects to the caregiver demographics of this study which could have accounted for the difference in P-SEMI scores. Gilmore and Cuskelly (2009) conducted a study with parents to establish a normative group to compare CSE with vulnerable groups when using the PSOC. The means of the efficacy subscale from the study was 4.41 (*SD* = .81) for mothers and 3.75 (*SD* = .98) for fathers (Gilmore & Cuskelly, 2009). In comparison to this study's PSOC mean for the total sample (*M* = 5.18, *SD* = .67), caregivers in this study had higher levels of CSE. The means from the GSE of the experimental group (M = 4.95, *SD* = .78) and the control group (M = 5.27, *SD* = .53) were slightly higher than a study conducted by Coleman and Karraker (2000) with a mean GSE value of 4.81 (*SD* = .77). Coleman and Karraker (2000) measured general self-efficacy with 145 mothers of 5 – 12 year old children without any specification of diagnosis or condition. Other studies measuring general self-efficacy of parents using the GSE and reporting scores on a 6-point Likert scale (as opposed to the 4-point scale in the way it was developed or using sum scores) is limited and thus challenging to compare GSE baseline results to more studies. In summary, this sample of caregivers held higher scores on the P-SEMI, PSOC and GSE compared to caregivers in other studies (Coleman & Karraker, 2000; Gilmore & Cuskelly, 2009; Williamson, 2016).

The results from the scales suggest that at baseline assessment, caregivers felt efficacious and their internal resources to parent were perceived to be sufficient to engage and respond to the demands in the occupation of parenting. Therefore, despite the majority of caregivers experiencing economic hardship (*n* = 55, 86% of caregivers earning less than R3200 per month for total household income)

CSE remained intact. Findings from a study by Elder, Eccles, Ardelt and Lord (1995) suggests that economic deprivation does not have a direct influence on CSE, but rather it is the subjective experience of financial adversity which has a negative impact on CSE. Thus, some caregivers who feel inundated with financial pressure can have lower CSE. There are, however, caregivers from low income groups who feel that they can cope and overcome difficult financial situations. Data from this study would seem to corroborate these findings viz a viz the experience of financial adversity for these caregivers are insufficient to affect CSE, despite the apparent economic hardship (Bandura, 1997; Elder et al., 1995).

A possible explanation for the high level of CSE could also be associated with the caregivers' self-evaluations influenced by comparison to other caregivers and children with HIV or illness in their communities (outside the GSH clinic). These caregivers had already exerted agency to access services required for their child's health. Health care services rendered from GSH as a tertiary level care facility were possibly more highly regarded than those at primary health care clinics in the local communities where peers might have attended. Many of the caregivers choose to remain at GSH for perceivably higher quality services. Furthermore, as the GSH clinic was further away than local clinics that other caregivers might have attended, it required more financial, energy and time resources from the caregiver. Comparison of peer norms can be used as a means for caregivers to judge their capabilities and inform self-appraisals that give a caregiver a sense of efficacy (Bandura, 1997). With this in mind, caregivers could perceive that they are able to better provide for their children with the extra effort that they put in for the best possible service in comparison to their peers. Should caregivers judge their capabilities to be competent through social normative comparison, whether based on actual performance or perceived performance, this can cultivate higher levels of CSE (Bandura, 1997). Furthermore, the caregiver sample in this study could have felt empowered, merely by taking advantage of the opportunity to participate in the study to promote development in their children, which could have influenced their CSE (Bandura, 1997).

Baseline results indicating relatively high CSE could have also been influenced by the caregivers' optimistic perceptions of their children's progress. When caregivers were asked at baseline about their children's learning, development and play skills, the majority of caregivers (*n* = 48, 75%) felt their children's skills were developing, on par or better than other children. Thus, the majority of the caregivers were not concerned about child outcomes and this could have influenced how they felt

about their role as a caregiver to facilitate these perceived outcomes. The structure of the question about how a caregiver felt about their child's development, learning and play skills was formatted similarly to a 5-point Likert scale with options that all compared the child's skills to "other children of the same age" (Appendix F: Demographic questionnaire). As the sample predominantly lived in low socio-economic circumstances, the reference point for the caregivers' perceptions of the skills of "other children" would likely have been compared to children in their local communities. South African children facing the compound effects of poverty are at risk of slowed development (Mathews, Jamieson, Lake, & Smith, 2014). Therefore, the "other children" the caregivers would have appraised to judge performance of their own children could have displayed learning, developmental and play below what is age appropriate for a typically developing child. Therefore, through comparing norms of what was seen around them, caregivers could have a lowered perception of what age-appropriate learning, development and play looks like and subsequently perceived their children to be developing on par. Furthermore, prior intervention had been primarily medically focussed and thus external feedback to the caregivers from professionals indicating the child's skill level of learning, development and playfulness was likely to be limited at baseline. Most of the children were not yet attending formal schooling and therefore not receiving detailed reports on their performance. Thus, caregiver perception through own observations would have likely been the primary informant on gauging child outcomes.

Although, data on caregiver knowledge of child development was not collected in this study, Hess, Teti and Hussey-Gardner (2004) conducted a study with a group of mothers of high-risk infants attending a developmental clinic which suggests that when maternal knowledge is high there is a positive correlation with CSE and maternal behavioural competence. However, there is also an inverse relationship when knowledge on child development is low, mothers also reported high levels of CSE and sense of competence (Hess et al., 2004). The authors propose that these mothers were naively confident, and suggested strategies to assist these mothers during intervention. Applying the conclusions to this study, it could mean that caregiver knowledge (high or low) of child development could have influenced CSE levels. As child development was not assessed it is unclear whether the caregiver's baseline knowledge of child development was sufficient or not. However, it is noted that Ayliffe and colleagues' (2013) study indicated knowledge of play development was poor in caregivers attending GSH and four other paediatric HIV clinics which could suggest that overall development

knowledge could also be poor in the population, but this cannot be concluded without sufficient data.

The order that the P-SEMI subscales were ranked at baseline were similar for both groups, with establishing discipline strategies ranked lowest and showing affection and empathy ranked highest. Results from Harty's (2009) study using the P-SEMI with a South African sample similarly revealed the subscale of showing affection and empathy as the highest ranked subscale for mothers of both typically developing children and children with disabilities. There are no other intervention studies that have used the P-SEMI and recorded the subscale results. Other studies measuring CSE using the Tool to measure Parenting Self-efficacy (TOPSE) were reviewed. The TOPSE consists of 9 subscales of parenting dimensions: (1) emotion and affection; (2) play and enjoyment; (3) empathy and understanding; (4) routines; (5) control; (6) discipline and boundary setting; (7) pressure; (8) self-acceptance; and (9) learning and knowledge. Intervention studies using the TOPSE similarly demonstrated that CSE in the subscale of emotion and affection was the highest subscale of the nine subscales at baseline (Bloomfield & Kendall, 2007, 2012; Kendall et al., 2013). Van Rijen, Gasanova, Boonstra and Huijding (2014) conducted a study using The Self-Efficacy for Parenting Tasks Index – Toddler Scale (SEPTI-TS) (Coleman & Karraker, 2003) which also has some similar subscales to that of the P-SEMI. The study results depicted that caregivers held the highest CSE in the subscale of nurturance, valuing the child, and empathetic responsiveness, in comparison to other subscales: play; instrumental care and establishment of structure and routines; and, discipline and limit setting (Van Rijen et al., 2014). Similarities can be seen between the subscales of emotion and affection from the TOPSE; nurturance, valuing the child, and empathetic responsiveness from the SEPTI-TS; and showing affection and empathy from the P-SEMI. The consistent high ratings of these subscales infers a trend which indicates that caregivers consistently believe that they are able to show affection and empathetic responsiveness. The aforementioned studies included populations of caregivers of children with disabilities and caregivers of children without specific health or developmental impairments (Bloomfield & Kendall, 2007, 2012; Harty, 2009; Kendall et al., 2013). This further suggests that the presence of risk factors such as HIV or disability does not affect caregivers' perception regarding their ability to provide affection and show empathy to their child. High CSE in showing affection and empathy could have implications for intervention, and interventionists should draw on this area of CSE as an area of relative strength.

The other P-SEMI subscales and similar subscales in the TOPSE of play and enjoyment, and, discipline and boundaries, were ranked differently when compared to other studies (Bloomfield & Kendall, 2007, 2012; Michal Harty, 2009; Kendall et al., 2013). The experimental and control group in this study both ranked establishing discipline strategies as the lowest CSE subscale on the P-SEMI. Similarly, studies using the SEPTI-TS had similar results in ranking the subscale of discipline and limit setting as the subscale with the lowest CSE for mothers (Meunier & Roskam, 2008; Van Rijen et al., 2014; Whittaker & Cowley, 2012). Results from Van Rijen et al.'s (2014) study ranked discipline as the lowest subscale for both groups of caregivers with and without children with known psychiatric or behaviour conditions. This suggests that this area of caregiving could be a generally lower area of CSE for parents irrespective of child conditions. As both groups in this study revealed establishing discipline as the lowest rank of CSE, this could suggest that managing child discipline in this population could be the area of childrearing where caregivers generally feel least efficacious, relative to other areas. This could have implications on intervention to focus on facilitating discipline strategies as an area of higher priority for caregivers.

The parental satisfaction subscale was significantly lower than the parental efficacy scores at baseline as indicated in the results. This implies that in this study the caregivers' sense of efficacy was higher than their feelings of satisfaction. This is contrary to other studies that have used the PSOC where the parental satisfaction subscale held consistently higher mean values compared to the parental efficacy subscale regardless of caregiver gender, child gender (Johnston & Mash, 1989; Ohan et al., 2000) or presence of disability (Harty, 2009). However, studies conducted by Gilmore and Cuskelly (2009) and Rogers and Matthews (2004) indicate a caregiver gender difference between the subscales where fathers had higher parental satisfaction in comparison to their efficacy scores and mothers had higher efficacy scores relative to their satisfaction scores. Although the sample of this study was not restrictive to biological parents, 61 (95%) caregivers were female of which 48 (75%) were the biological mother and thus, this study comprised too few male participants to run analyses to support or refute this notion.

6.3 Changes in caregiver self-efficacy within groups in the P-SEMI between assessment points

The aim of the study was met as levels of CSE were comparable between the experimental and control group following PICIHBI. The benefits of meeting this aim are discussed later in the chapter. Although there was not a significant increase in CSE from baseline to post-test in either group, there was a significant decline from baseline to mid-test, followed by a significant increase from mid-test to post-test in the P-SEMI scale for both groups. This could imply that involvement in the research study could have had an effect on CSE. Some possible explanations of the fall and rise pattern in CSE are discussed below.

Following baseline assessment, PICIHBI commenced which started a new learning process for the caregivers. This included knowledge transfer and skill development to facilitate child learning, development and play. This learning may have been recognised as a new perceived challenge which could have brought up questions about inherent performance efficacy (Bandura, 1997; Cervone et al., 2006). This could have led the caregivers to redefine their caregiving roles and expectations and reflect more self-critically on their performance, altering their self-judgements which could have lowered their CSE. Although the conventional OT intervention did not focus on the development of the caregiver skills, the therapist might have had some discussion with caregivers around child learning, development and play and the needs of their children which could have had a similar effect to that of the experimental intervention.

Another factor that could have influenced the decrease in CSE between baseline and mid-test was the generally poor child performance results that the caregivers received from the parallel studies. Following baseline assessment, results from the parallel studies investigating child outcomes were drawn up in a report for feedback to the caregivers (and medical file), displaying the child's performance in the domains of development, learning and playfulness. One of the assessments conducted at baseline as part of Meissner, Gretschel and Ramugondo's (2016) parallel study was the Griffiths Mental Developmental Scales – Revised and Extended Revised (GMDS-R & ER) (ARICD, 1996, 2006). The study investigated changes in the developmental outcomes of children aged 6 months to 5 years within the same caregiver-child sample as this study. The GMDS-R & ER baseline assessment indicated that the total score fell in the category of borderline mental retardation according to the interpretation labels from the GMDS-R & ER (ARICD, 1996, 2006; Meissner et al., 2016). Although the report and feedback to the caregivers did not use this specific descriptor for their children, it was indicated that the results from the total scale and subscales were well below

average for most children. Otto, Gretschel and Ramugondo's (2016) parallel study on learning outcomes for children aged 5 to 8 years, within the same caregiver-child sample as this study, also used some of the Griffiths Mental Development Scale-Extended Revised (GMDS-ER) subscales and the Beery-Buktenica Developmental Test of Visual Motor Integration (Beery & Beery, 2006) to assess learning outcomes. Similarly, Otto et al.'s (2016) baseline results indicated results with the descriptions of "low average" and "borderline delay" for the GMDS-ER subscales and "below average" scores for motor co-ordination and "low" scores for visual motor integration and visual perception according to the Beery test (ARICD, 2006; Beery & Beery, 2006; Otto et al., 2016). Another parallel study by Uys, Ramugondo and Cordier (2016) investigating playfulness outcomes in children aged 10 months to 8 years within the same caregiver-child sample, also found that the average playfulness of the child sample at baseline was lower than for those of typically developing children. As discussed earlier in the chapter, at baseline the caregivers' (*n* = 48, 76.19%) predominant perception about their children's development, learning and play skills was that they were developing on par or better than other children their age. Subsequently, the caregivers received the (generally poor) results from several norm referenced tests from health professionals indicating their child's performance compared objectively to children of a similar age. Furthermore, during intervention, caregivers could have gained more detailed insight into age-appropriate development, learning and play norms. An important component in PICIHBI was to discuss and understand development, learning and play skills and what is expected of the child at different ages. Although this might not have been concentrated on in the conventional intervention, the therapist might have highlighted to the caregivers the specific skills needed in their children. This insight could have highlighted gaps to the caregivers where their children fell short. Thus, upon receiving the above information from the reports and intervention, this could have consequently shifted the caregivers' initial view of how their children were progressing. Child outcomes could have then prompted caregivers to reassess their level of self-efficacy in the occupation of parenting and their ability to support their children's development. With the altered perceptions of how their children were progressing, caregivers may have felt less efficacious in their caregiving role.

Social comparison, "the process of thinking about information about one or more other people in relation to the self", might be another factor influencing changes in CSE (Wood, 1996, p.520). Although vicarious experience has been posed as a source to enhance self-efficacy (Bandura, 1997), social comparison as a form of vicarious experience could be translated in a positive or negative way

(Carmona, Buunk, Dijkstra, & Peiro, 2008). There could have been positive effects on CSE from observation of others attainments through which caregivers could internalise a sense of being able to also fulfil the caregiver role in the same positive manner. However, caregivers might have contrasted themselves to other caregivers, the therapist or group assistant and their engagement with children. Thus, this could have also lead to an opposing effect on CSE where the caregiver would have negatively contrasted their fulfilment of their role to others who might have been perceived to be better in the role. A meta-analysis study on social comparison determined variables that could influence the process of social comparison (Gerber, Wheeler, & Suls, 2017). Findings suggest that individuals were more likely to compare themselves to someone better off than themselves, with a stronger effect of comparison with others that were more "local" (sharing group membership) (Gerber et al., 2017). Individuals were also more likely to contrast their self-evaluations as opposed to assimilate self-evaluations in relation to others (Gerber et al., 2017). Gerber and colleagues (2017) thus suggest that people perceive themselves to be good but can have an element of uncertainty in their self-appraisal. To seek validation of their self-appraisal, people compare themselves to someone with whom they can identify but this tends to be an upward contrast with someone who is perceivably better off and, therefore, this can lead to self-deflation (Gerber et al., 2017). Although Bandura's sources of self-efficacy speak to self-efficacy being facilitated through vicarious experience (Bandura, 1997), one might also consider that the caregivers might not have been empowered through seeing others modelled attainments but rather have had comparisons and deficits in their caregiving role highlighted.

A variable that could have influenced the changes in CSE could be related to timing of the assessment and intervention periods and related situational contextual factors. Baseline and post assessment period both happened in the middle of the year, whereas the mid assessment period occurred at the end of the one year and continued to the start of the following year. The end and beginning of a year can be a season for evaluation, often spurred on by events such as receiving school and work evaluation reports, and reflections on achievements through the year. Thus, the frame for self-evaluation during this season could be different and influence self-efficacy.

6.4 Changes in the PSOC, GSE and P-SEMI subscales within each participant group

Although the P-SEMI total score showed significant difference between the three test points, only minor, non-significant changes occurred between test points within the PSOC, PSOC subscales, GSE and P-SEMI subscales ($p > .05$). This indicates that neither intervention had an effect on these other scales and subscales.

A study conducted by Gardner, Burton and Klimes (2006) that also took place in a low income population, investigated the effect of the Webster-Stratton parenting programme for managing child conduct problems. Although a significant increase in the total score of the PSOC was seen, the researchers found that when the PSOC subscales were separated, the intervention had an effect only on the parenting efficacy subscale and not the parental satisfaction subscale (Gardner et al., 2006). These results are plausible considering the intervention focussed more on cognitive-behavioural approaches to managing child behaviour rather than coping and emotional appraisal strategies which are more associated with feelings of satisfaction. Similarly, PICHIBI also focussed more on practical skills for caregivers to stimulate child development and one would have expected a greater increase on the efficacy subscale than on the satisfaction subscale in the PSOC. However, as mentioned, there was no significant difference in the total or subscales of the PSOC.

Although the GSE scale showed no significant difference between groups with the total sample (N = 64) at baseline, when comparing baseline scores of the caregivers who completed all assessments at all three time points (n = 39), there was a difference between the groups. The control group had higher values than the experimental group which was maintained to post-test. The reason for this difference between groups at baseline is unknown and current data does not provide reasonable explanation of this difference. Barlow and colleagues (2008) found statistical differences on the GSE and the Parent's Self-Efficacy Scale (total scale) for the parent intervention group in comparison to the control group, however, these effect sizes were small (.08 - .14). Furthermore, the study indicated that there was also a decrease in the GSE in the control group, so whilst there was a small increase in GSE in the intervention group, the significant difference in GSE cannot be accredited to the intervention programme attendance. Similarly, this study did not demonstrate within group change between test points.

A possible reason that there were significant changes between test points on the P-SEMI but not the PSOC and GSE could be that the latter scales are more generalised measures. Coleman and Karraker (2000) highlight four types of self-efficacy measures including general self-efficacy measures, such as the GSE that is not specific to a domain like parenting, as well as domain-general measures, such as the PSOC where there is a global measurement of self-efficacy relating to general capability of parenting. The other types of measures of self-efficacy are domain-specific measures and task-specific measures, such as the P-SEMI. As the interventions targeted specific developmental domains and related caregiving tasks, questions asked in the P-SEMI could be more associated to outcomes of the interventions in comparison to the PSOC. Furthermore, the GSE is even more generalised than the PSOC and not related to parenting. Thus, the interventions might not have had such a direct effect on the GSE construct. This is in line with Bandura's (1989) view that domain-specific measures will determine related behaviour with greater validity than that of general measures. Coleman and Karraker (2000) investigated inter-correlations between various self-efficacy scales, including those that measured general self-efficacy and those that were considered domain specific measures of self-efficacy, with a sample of mothers. The authors propose that although the results suggest that domain specific CSE contributes to wider forms of self-efficacy it should be noted that the constructs in the measures obtain conceptually different data and the results also had a large proportion of unexplained variance (Coleman & Karraker, 2000). Thus, the effect of caregiver interventions on GSE should be considered with caution.

Although there were significant changes in the P-SEMI total scores, the subscales did not demonstrate significant changes when separated. This is contrary to the results of other studies that have used scales with similar CSE domains such as the TOPSE. Bloomfield and Kendall (2007) had an increase on all subscales on the TOPSE measuring instrument following a parenting programme. Furthermore, in the subscales ‘emotion and affection’; and ‘routines’, Bloomfield and Kendall (2007) also found there to be a significant change from post assessment to the 4 month follow up assessment which proposes that the positive change in CSE from baseline to the end of the programme was retained. Similar to the emotion and affection subscale in the TOPSE is the subscale of showing emotion and affection in the P-SEMI which was the highest subscale at baseline. It had a mean sum score of 38.97 with the potential range of 6 – 42 and thus had little room for increase. Although this study does not provide conclusive results to suggest that parenting intervention

impacts the P-SEMI subscale of showing emoting and affection, future studies using the P-SEMI could take note of the potential for maintained change in this subscale.

6.5 Intervention attendance

Intervention attendance could have had an influence on the results and should be looked at in more detail in future studies to better understand the results as well as for considering intervention development and implementation in the future.

The difference in intervention attendance between the groups is noteworthy. Both groups had a third of the sessions attended by caregivers over the duration of the intervention period. Both groups also had a decline attendance rate after mid-test. However, the control group had a smaller decrease in attendance between the assessment points (34.44% to 32.22% attendance) and thus maintained attendance better than that of the experimental group (40.95% to 25.71%). Although there is no data to deduce specific reasons for the difference in attendance between groups some explanations are posed for further exploration. Caregivers attending PICIHBI were required to be actively involved in the sessions including participating in discussion and mediating play activities with children. Whereas, caregivers attending the conventional intervention, who were not necessarily required to be in the room with the child, were likely to have played a more passive role, including observation and being a recipient of activity suggestions from the OT (as opposed to coming up with their own ideas). PICIHBI requires more of the caregiver and also could lead to conditions where the caregiver could feel more exposed or intimidated, despite efforts of the therapist to try prevent these conditions. Micari and Drane (2011) note that although there are many benefits to small group learning that can foster greater learning potential and be an environment of support, it can also be a threatening and intimidating environment to some participants with negative consequences of social comparison. It should also be noted that the intervention session time differed between PICIHBI sessions and conventional therapy sessions. Each intervention had 45 minutes per session with the child but PICIHBI had a further 45 minutes with the caregivers alone. The extra time commitment to PICIHBI could have had an impact on the caregivers' willingness to participate, given the many other activities that occurred on clinic days that competed for the caregivers' time. Another consideration could be that when a caregiver did not attend a PICIHBI group session, the group would continue with remaining members. Caregivers in the

experimental group might have perceived that it would make less of a difference to the intervention therapist if they were not there as the group would still continue as opposed to the control group that had intervention appointments and absence would be more noticeable. Thus, there could have been a greater sense of fidelity in the control group. It is also possible that conventional therapy might have been perceived as more valuable and specific to the child.

Although there was a difference in attendance between test points between groups, the attendance was still generally poor in both groups over the intervention period. Similar to the above-mentioned time commitment required in the PICIHBI group, and, although intervention in the control group was shorter, there was also a time commitment for the caregiver to attend conventional therapy. This means that both interventions would require time of the caregiver when trying to also tend to other clinic activities, sometimes including their own clinic appointment if the caregiver is also an HIV-positive patient at the clinic. Caregivers could have had a lower priority to attend occupational therapy interventions, as the newer and possibly less understood clinic activity, in comparison to other, long-standing, clinic activities including: attending doctor appointments (child and caregiver appointments where applicable), taking blood samples, going to the pharmacy, seeing a counsellor or completing Kidzpositive beadwork projects for which they were paid. Intervention therapists coordinated with doctors regarding the queue to be seen so that should a caregiver be attending one of the interventions when they were called by the doctor they would remain at the top of the list to be seen next after the intervention session. Despite explaining this system to the caregivers, informal feedback from the intervention therapists reported that some caregivers would still insist that they wanted to wait for the doctor first so that they would not miss being called, which sometimes resulted in missing intervention. This competing for time amongst other activities could have had an impact on the attendance for both interventions.

Another factor to consider regarding attendance is the timing between sessions. More frequent sessions could have also influenced the momentum of intervention and consequent attendance. Wittkowski et al.'s (2016) systematic review indicated that most of the group based interventions conducted improved CSE. The review also indicated that the vast majority of the included studies reported intervention that took place on a weekly basis and there were no studies in the review that exceeded a total duration of 15 weeks (Wittkowski et al., 2016). The dosage of parenting interventions discussed in this review is vastly different to the interventions in the current study

(monthly intervention sessions for the duration of one year). A weekly intervention dosage might have had more of a direct effect on CSE compared to a monthly dosage. Furthermore, assessment did not always happen straight after intervention had ended. If caregivers missed the post intervention appointment another assessment appointment would have been booked that could have been up to 2 months following the last intervention session. This extended time between intervention and assessment could have allowed for other variables external to the study to also influence CSE validity of results.

6.6 Conclusion to discussion

The results of the study reveal change in CSE in the experimental compared to the control group which indicates that we can accept the hypothesis, i.e. change in CSE levels are not worse in the PICIHBI compared to conventional OT intervention. Baseline results of the PSEMI, PSOC and GSE are higher than other studies investigated utilising the same instruments suggesting that the sample of caregivers felt efficacious at the time of baseline. The decline in CSE on the P-SEMI from baseline to mid-test and increase from mid-test to post-test in both groups suggests that the participation in the study and interventions influenced CSE. Possible explanations of this change in CSE were outlined in this chapter and included: starting a new learning process; becoming more aware of the generally poor child developmental outcomes through the collateral study reports and feedback; and, caregivers comparing themselves to others perceivably better off. Attendance was generally poor for both interventions and could have influenced the strength to which the interventions specifically influenced CSE.

7 Conclusion and Recommendations

7.1 Conclusion

This study concludes that the effectiveness on CSE is not inferior in a caregiver-directed, group-based intervention, (PICIHBI) to conventional occupational therapy directed at the individual child, in a sample of caregivers of HIV-positive children. Superiority of the effectiveness of PICIHBI on CSE has not been established.

The data at baseline presented high levels of self-efficacy suggesting that the group of caregivers in the study felt efficacious at baseline. This particular group of caregivers were already exercising their sense of agency in accessing clinic services in and willing to participate in the study to promote development in their children which could have contributed towards a group of caregivers with high levels of CSE at baseline. Furthermore, the caregivers perceived development, learning and play skills to be progressing age appropriately or better in their children which could have informed the caregivers' sense of successfully fulfilling their caregiving role and consequently influencing their CSE. Significant change was found on the P-SEMI total scale within each group between baseline and mid-test, and, mid-test and post-test, however, there was no significant change between baseline and post-test in either group. The decline in CSE on the P-SEMI at mid-test is noteworthy suggesting there was a change in self-appraisal in task-based caregiver domains with intervention commencement. Possible explanations of this pattern are outlined in the discussion chapter, however, further investigation and data is needed to make sound deductions. There were no significant changes over time in the P-SEMI subscales, PSOC, PSOC subscales and GSE within group.

Although there were high levels of CSE at baseline, the levels of CSE changed through the intervention period, thus the need to explore change of CSE through intervention is still valid, as supported by literature that suggests caregivers of vulnerable children require support (Burns et al., 2008; Dorsey et al., 1999; Foster et al., 2006; Potterton et al., 2007). A study by Roskam, Brassart, Loop, Mouton and Schelstraete (2016) also indicate that intervention that manipulates CSE can have a widespread positive effect on other caregiving variables including: behavioural and emotional responsiveness, positive affect, irritability and support. Thus, addressing CSE in intervention remains valuable.

The ranked order of the P-SEMI subscales at baseline were described. Showing affection and empathy was the highest subscale and establishing discipline strategies as the lowest subscale within both groups, consistent with other studies using scales with similar subscales. This suggests that these subscales could be consistently high or low compared to other caregiver domains across population groups of caregivers and can be further investigated in future studies.

The purpose of the study was to inform future practice by determining whether a caregiver-mediated intervention had comparable CSE results to an existing, child-mediated service delivery model to promote development in children with HIV. The similar results in CSE for the different intervention models provide support for rethinking structure and mode of OT interventions to promote development, learning and play in similar contexts across South Africa. Although PICIHBI does not show superior results and both interventions have value, using a group-based caregiver-directed interventions as an alternative service delivery model holds many benefits. These include:

- Development of skills for both the caregiver and child (mediated through the caregiver)
- Maintained intervention allowing for more frequent opportunities for stimulation and development for the child than would be afforded at clinic appointments
- Intervention for the child based in the home environment and thus more contextually relevant to the child and family's everyday life
- Efficient use of limited human and financial resources where a larger client base can be reached through a group format

The non-inferior results between interventions suggests potential for further development and investigation into the impact of PICIHBI and implementation as a viable model of service delivery in the public health sector given other benefits of PICIHBI. However, limitations regarding the intervention and poor attendance will first need to be addressed in order for further study to be feasible.

7.2 Completion of the study

Results and analyses from the study will be shared with those supporting the study financially and practically, including: The Kidzpositive Family Fund, the DG Murray Trust, and the Groote Schuur

Hospital clinic staff. The results will be combined and analysed with the results from the parallel studies for a comprehensive picture of the effectiveness of conventional occupational therapy compared to PICIHBI on CSE and child outcomes of development, learning and playfulness. Learning from the research will be discussed with the team of occupational therapists involved in the development of PICIHBI, and the team will review how this should inform further development of the intervention for best practice.

7.3 Strengths and contributions of the study

This study presented a number of strengths and contributions:

- A trial examining the effectiveness of occupational therapy intervention on CSE in caregivers of HIV-positive children has not been conducted before. Thus, this study provides exploratory data which explores caregiver outcomes following in intervention in this population group. This is also the first time the impact of PICIHBI has been studied (along with the parallel studies) and provides data to inform the development of occupational therapy service delivery models (group vs conventional one-to-one) best suited to HIV-positive children and their caregivers in South Africa.

- The main finding indicates that PICIHBI and conventional interventions have a comparable impact on CSE. With the limited number of OTs and the large population of HIV-positive children in South Africa and their related developmental needs requiring intervention, implementing group-based intervention, like PICIHBI, would have a larger reach than conventional occupational therapy which is typically on an individual basis. Group based interventions are reported to provide a more cost-effective model for service delivery.

- Although, PICIHBI does not demonstrate significant increase in CSE from baseline to post-assessment, the experimental group displayed higher CSE means in the subscales of play and learning, compared to the control group, although these results were not significant. This indicates that parents attending the group intervention sessions derived some benefit from the programme compared to the conventional therapist only model. Although these results are not significant they suggest that further research into the value of PICIHBI is warranted. Intervention attendance and duration could have contributed towards non-significant

results and revising the intervention to address these concerns could provide more significant results in the future. Recommendations for the intervention are given later in the chapter.

- Conducting a randomised controlled trial to investigate the effect of PICIHBI was a strength of the study as this design is considered to present the most reliable evidence on the effectiveness of interventions (Akobeng, 2005). The study followed CONSORT guidelines for parallel group randomised trials which aided further validity in the study (see Appendix B: CONSORT checklist) (Moher et al., 2010).

- The study provided data collection in the participants home language of English, Afrikaans or isiXhosa (the dominant language of the participants). Furthermore, PICIHBI also had a translator present for isiXhosa. This provided more accurate measurement and intervention that was best understood in the caregivers' home languages.

7.4 Limitations

In spite of the strengths of the study, there are also limitations to be noted.

- The study sample was small and underpowered compromising the validity of the results and interpretations.
- The study was located in one paediatric HIV clinic at GSH. Using one geographic location limits the generalizability of the results that could be applied to other caregivers with HIV-positive children in Cape Town.
- The baseline results are relatively high and query whether intervention to target CSE in this population is necessary. CSE in this particular South African population of HIV-affected caregivers from low-income areas would need further exploration.
- Effectiveness of the conventional occupational therapy has not been established.
- As mentioned previously, the participating group of caregivers could have represented a particular subgroup of caregivers of HIV-positive children that were already accessing support and services and willing to commit to intervention. Consequently, participants of the study may have felt that they were coping well and had a different baseline CSE compared to those that did not consent to participate in the study.

- Participant drop-out of the study was relatively high with many caregivers not attending all three assessment time points. Intervention attendance was also poor for both groups. The location of the study might have affected attendance of the assessments and intervention as it was a substantial distance away from most participants' residential areas which meant additional costs when the standard transport money supplied was not sufficient. However, the attendance of the intervention in the study demonstrates what would be characteristic attendance going forward with the same intervention models implying that carrying out this intervention in the same way would have low attendance. It would be interesting to compare attendance of the intervention at a more local location. This could point to restructuring the setup of the intervention to be as convenient as possible for the caregivers as well as to foster momentum in attendance. Data collection procedures, intervention and retention would need to be addressed prior to further research on a larger scale.
- Empirical studies outline gender differences in the way in which CSE operates (Bandura, 1997; Gilmore & Cuskelly, 2009; Ohan et al., 2000; Rogers & Matthews, 2004). However, as female participants predominated in this study gender differences in CSE were not explored.
- Due to time constraints, there was no follow up assessment after intervention was complete. A follow-up assessment typically occurs at a 3-6 month interval post intervention, and is helpful in determining the maintained effect of interventions.
- There was no data collection tracking implementation of PICIHBI at home. This hinders a full understanding of the carryover of skill development applied at home and how it affects CSE
- The study involved multiple data collectors. Although a protocol was established with verbal and written instructions for administration of the instruments, including checking all instrument items were completed by the participant on hand in, there was still missing data. This protocol was re-emphasised prior to all data collection time points. Missing data was handled following literature guidelines (Cheema, 2014) but there could have been greater data integrity if the dataset was complete. Furthermore, the inconsistencies with the multiple data collectors also resulted in the incorrect labelling and handling of 2 participants which diminished the sample size.
- Although confidentiality was emphasised and upheld with participants, it is possible that participants responded more positively than they would have with complete anonymity. Questionnaires included participant codes instead of names, honest responses were encouraged and it was emphasised that there would be no repercussions from the clinic or

researchers to the responses participants gave. However, as the participants were known in the clinic environment and administration was conducted in person where completed questionnaires would have been handed back to the data collector, it is possible that participants could have been subject to social desirability bias. Unfortunately, complete anonymity would have been difficult to achieve with needing to track participants across time with multiple assessment points where assessments would need to be linked.

- The study also lacked data that recorded feedback from participants which limited understanding of particular variables such as reasons for attendance and non-attendance as well as the experience of the intervention that could inform development of the intervention in structure, content and facilitation.

7.5 Recommendations

7.5.1 Recommendations for research

- Further research into the need to target CSE in this particular population of South African caregivers from low income areas caring for HIV-positive children would be necessary. This could be compared to South African caregivers from low income areas caring for children without any known health conditions. Research could also include mixed methods with qualitative data which this study did not collect.
- Following research that indicates need to target CSE as a necessary outcome for this population, as well as addressing retention and intervention components indicated below, the study could be reproduced with a superiority study design and then a larger sample size. A study could be conducted across various locations for a higher powered and more generalizable study. Other locations should include other hospital-based clinics and local clinics in the community as well as urban and rural settings across the country. The intervention could also be considered to take place in nonclinical settings such as non-profit organisations like Beautiful Gate, the site where PICIHBI was first implemented and where participation and attendance appeared to be better.

- Other caregiver variables that are found in literature to be associated with CSE, such as life events, caregiver health, well-being, depression, anxiety and caregiver knowledge about child development, should be measured and analysed across time (Bandura, 1995; Hayes et al., 2008; Hess et al., 2004; Jones & Prinz, 2005; O'Neil et al., 2009; Sevigny & Loutzenhiser, 2009). A regression analysis could be used to provide evidence of determinants of CSE in this population. Qualitative research could also be conducted to further understand factors or circumstances that could impact CSE.

- An analysis of the caregiver-child relationship and the co-occupation of play with the HIV-positive child in relation to CSE and child development could be undertaken to generate information to further inform intervention.

7.5.2 Recommendations for practice:

- Restructuring of the intervention programmes should be considered in terms of location and frequency to enhance attendance. Factors that affect intervention attendance and implementation of gained skills at home, could be tracked and explored.

- As caregivers are intended to implement intervention with their children, following recommended practice in early intervention outlined by Woods, Wilcox, Friedman and Murch (2011), they could be more involved in the intervention design, content and related plans.

- Considering that emotional well-being of HIV-positive caregivers has been found to have a significant relationship with self-efficacy (Okeke, 2016), incorporating a domain of caregiver emotional well-being more directly into PICIHBI, in addition to skills based training, could be explored.

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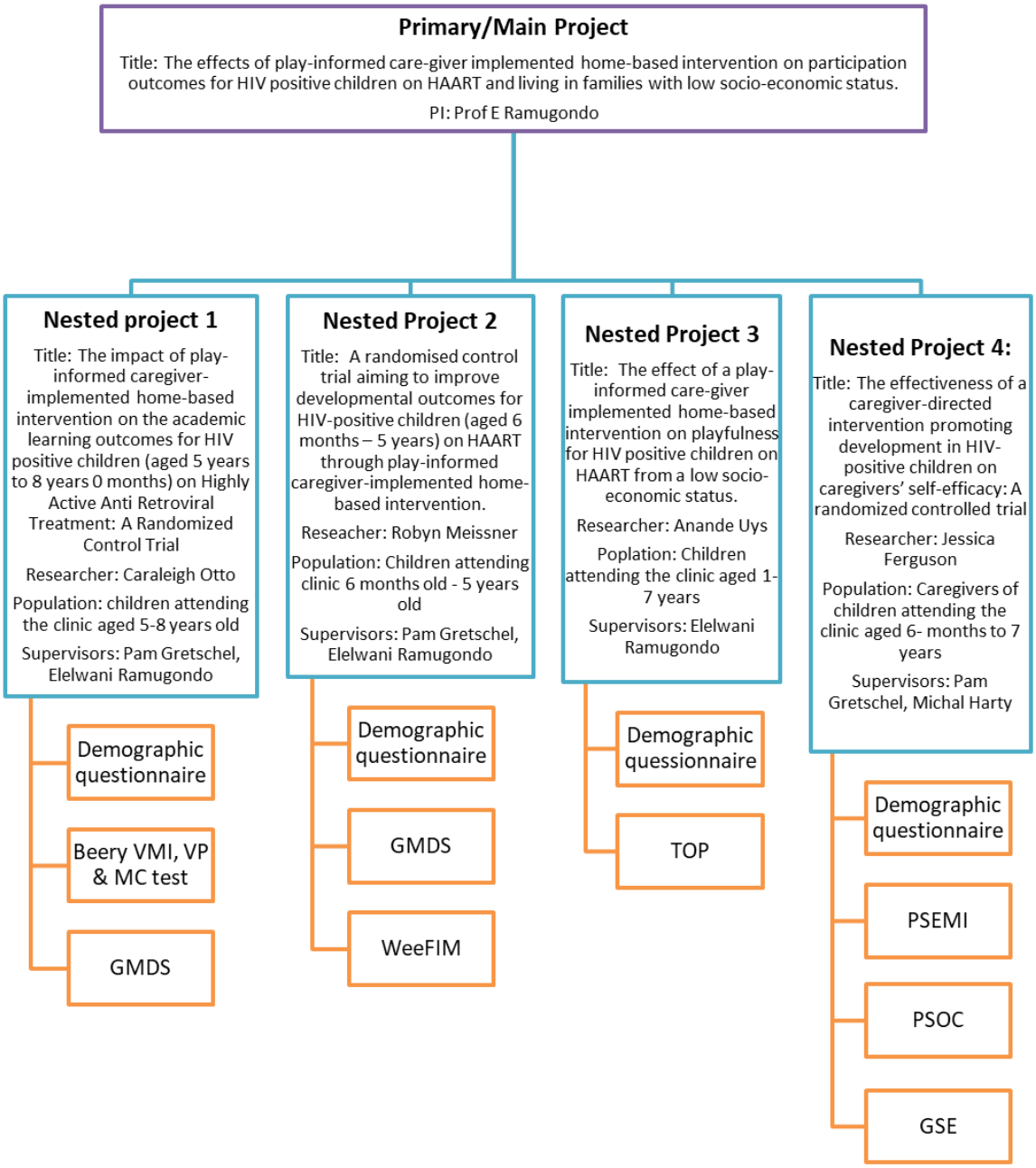
9 Appendices

9.1 Appendix A: Project Map



9.2 Appendix B: CONSORT checklist

CONSORT 2010 checklist of information to include when reporting a randomised trial

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a randomised trial in the title	0
	1b	Structured summary of trial design, methods, results, and conclusions (for specific guidance see CONSORT for abstracts)	2
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale	14
	2b	Specific objectives or hypotheses	41
Methods			
Trial design	3a	Description of trial design (such as parallel, factorial) including allocation ratio	39
	3b	Important changes to methods after trial commencement (such as eligibility criteria), with reasons	N/A
Participants	4a	Eligibility criteria for participants	43
	4b	Settings and locations where the data were collected	42
Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	30
Outcomes	6a	Completely defined pre-specified primary and secondary outcome measures, including how and when they were assessed	47
	6b	Any changes to trial outcomes after the trial commenced, with reasons	N/A
Sample size	7a	How sample size was determined	44
	7b	When applicable, explanation of any interim analyses and stopping guidelines	44
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	45
	8b	Type of randomisation; details of any restriction (such as blocking and block size)	45
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	45
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	44 - 45
Blinding	11a	If done, who was blinded after assignment to	45

		interventions (for example, participants, care providers, those assessing outcomes) and how	
	11b	If relevant, description of the similarity of interventions	37
Statistical methods	12a	Statistical methods used to compare groups for primary and secondary outcomes	54
	12b	Methods for additional analyses, such as subgroup analyses and adjusted analyses	54
		Results	
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were randomly assigned, received intended treatment, and were analysed for the primary outcome	59
	13b	For each group, losses and exclusions after randomisation, together with reasons	62
Recruitment	14a	Dates defining the periods of recruitment and follow-up	42
	14b	Why the trial ended or was stopped	-
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	63
Numbers analysed	16	For each group, number of participants (denominator) included in each analysis and whether the analysis was by original assigned groups	62
Outcomes and estimation	17a	For each primary and secondary outcome, results for each group, and the estimated effect size and its precision (such as 95% confidence interval)	65 -75
	17b	For binary outcomes, presentation of both absolute and relative effect sizes is recommended	N/A
Ancillary analyses	18	Results of any other analyses performed, including subgroup analyses and adjusted analyses, distinguishing pre-specified from exploratory	75
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	52
Discussion			
Limitations	20	Trial limitations, addressing sources of potential bias, imprecision, and, if relevant, multiplicity of analyses	96
Generalisability	21	Generalisability (external validity, applicability) of the trial findings	96
Interpretation	22	Interpretation consistent with results, balancing benefits and harms, and considering other relevant evidence	79
Other information			
Registration	23	Registration number and name of trial registry	2
Protocol	24	Where the full trial protocol can be accessed, if available	Not in dissertation, available at UCT FHS
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	In protocol

9.3 Appendix C: Ethical approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492 • **Facsimile** [021] 406 6411
Email: Sumayah.ariefdien@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

12 February 2015

HREC/REF: 084/2015

Mrs P Gretschel
Occupational Therapy
Health & Rehabilitation Sciences
F-45-OMB

Dear Mrs Gretschel

Project Title: THE IMPACT OF A PLAY-INFORMED CAREGIVER-IMPLEMENTED HOME-BASED INTERVENTION ON CAREGIVERS' SELF-EFFICACY TO PROMOTE LEARNING, DEVELOPMENT AND PLAYFULNESS IN THEIR CHILDREN WHO ARE ON HIGHLY ACTIVE ANTI-RETRO VIRAL TREATMENT (MSc candidate- J Ferguson)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above mentioned study.

Approval is granted for one year until the 28 February 2016.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

We acknowledge that the following student:-Jessica Ferguson is also involved in this project.

Please note that the on-going ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Hrec/ref:084/2015

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: shuretta.thomas@uct.ac.za
Website: www.health.uct.ac.za/research/humanethics/forms

17 September 2013

HREC REF: 560/2013

A/Prof E Ramugondo
Occupational Therapy
Health & Rehab
F56.76, OMB

Dear A/Prof Ramugondo

PROJECT TITLE: THE EFFECTS OF PLAY-INFORMED CARE GIVER IMPLEMENTED HOME-BASED INTERVENTION ON PARTICIPATION OUTCOMES FOR HIV POSITIVE CHILDREN ON HAART AND LIVING IN FAMILIES WITH LOW SOCIO-ECONOMIC –STATUS

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th September 2014

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/research/humanethics/forms)

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS
Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

s.thomas

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.9.2015
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	26/9/14

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	25/09/2014		
HREC REF Number	HREC REF: 560/2013	Current Ethics Approval was granted until	30 September 2014
Protocol title	The effects of play-informed care-giver implemented home-based intervention on participation outcomes for HIV positive children on HAART and living in families with low socio-economic status		
Protocol number (if applicable)	N/A		
Are there any sub-studies linked to this study?	☐√ Yes ☐ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note:** A separate FHS016 must be submitted for each sub-study.	PhD - HREC/REF 605/2012: This is not strictly a sub-study, but a parallel one, focussed on the design process of the intervention in the main study. It followed action research methodology within a case study approach. Masters Sub-Studies: Other than being true sub-studies, with a separate bigger study, these in fact make-up the bigger study, with the Masters students as co-researchers to the main study. This caused immense confusion for us early on, elaborated on further under Progress of Study. These Masters studies are under-going departmental research review, with 3 of 4 having just submitted rebuttal letters and revised proposals last week.		
Principal Investigator	A/Prof Elelwani Ramugondo		

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

9.4 Appendix D: Permission letters to conduct research to institutions

9.4.1 Letter of permission to Department of Health to conduct research

Faculty of Health Sciences
School of Health and Rehabilitation Sciences
Divisions of Occupational Therapy
F45 Old Main Building, Groote Schuur Hospital,
Observatory 7925
Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323
Internet: www.uct.ac.za

02 October 2013

Western Cape Department of Health

To Whom It May Concern:

This is a formal request for permission to conduct a research study on a population comprised of HIV positive caregiver-child dyads who attend a paediatric out-patients clinic at Groote Schuur Hospital. The proposed study aims to investigate effects of play-informed care-giver implemented home-based intervention (PICIHBI) on participation outcomes for HIV positive children (Aged 6 months to 8 years old) on Highly Active Anti-retroviral Treatment (HAART) and living in families with low socio-economic status. PICIHBI will be compared with standard one-on-one occupational therapy intervention to see if it will produce equivalent or even greater improvement in child learning, development and play participation, and greater efficacy in caregivers in promoting these indicators. There are well-established negative long-term consequences for learning and development for children affected with Acquired Immune Deficiency Syndrome (AIDS). While HAART has proven to be effective in prolonging life expectancy in children living with HIV/AIDS, access to comprehensive health care is critical for these children to continue enjoying quality of life. Caregivers of HIV+ children in South Africa often face contextual challenges that often limit their ability to support their children's optimal participation in learning, development, self-care and play. Consequently, the potential of these children to meet their participation needs as adolescents and adults is compromised.

There are limited studies detailing what may be appropriate and possibly effective responses to developmental, functional and participatory challenges for children infected with HIV, especially those on ART or HAART. Given that home-based intervention has been proven to be effective in improving cognitive and motor development for HIV positive children from families with low SES, and may consequently impact functional and participation outcomes for such children, this kind of intervention may relieve the cost burden on the South African state for rehabilitation services.

Possible positive impact on learning, development, self-care and play for HIV infected children through PICIHBI may hold important promise for early childhood development in the country. A description of appropriate PICIHBI for families with low SES will inform relevant occupational therapy in South Africa. Efficacy in promoting children's meaningful and productive participation in life will be affirming for both caregivers and therapists.

The study will involve 160 caregiver-child dyads over a year. Data will be collected using the Griffiths Mental Development Scales – Revised & Extended Revised (GMDS – R & ER) and the Test of Playfulness (TOP) on children aged 6 months to 8 years old, and Parenting Sense of Efficacy Instrument (P-SEMI) on the caregivers at base-line and twice at six monthly intervals. Intervention in both the experimental and control group will occur monthly, following the same scheduling currently followed for clinic visits.

The study will adhere strictly to ethical principles as outlined in the Declaration of Helsinki (Seoul version, 2008). Ethics approval has been obtained from the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town (HREC Reference number 560/3013).

Caregiver informed consent as well as assent from children aged 7 to 8 years old will be sought before participation in the study resumes. There will be no coercion of any form in order to gain participation from the study population and each caregiver-child dyad may withdraw from the study at any point in time, free of prejudice should they so wish. No personal information will be collected as data during the study. The relevant hospital management personnel will be approached to seek consent to conduct this study following a positive response from the Department of Health.

Please forward any question or concern you may have regarding this research to contact details furnished below.

Principal Investigator:

A/Prof Professor Elelwani Ramugondo

Elelwani.Ramugondo@uct.ac.za

021- 406 6048

Chairperson of the UCT faculty of Health Sciences Human Research Ethics Committee:

Professor Marc Blockman

021- 406 6496

9.4.2 Letter of approval to conduct research

Western Cape Government
Health

GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bhavna Patel
E-mail : *Bhavna.Patel@westerncape.gov.za*

Associate Professor E. Ramugondo
Occupational Therapy
Health & Rehabilitation
F56.76 – Old Main Building

E-mail: elelwani.ramugondo@uct.ac.za / paul.roux@uct.ac.za

Dear A/Professor Ramugondo

RESEARCH PROJECT: The Effects of Play-informed Care Giver Implemented Home-Based Intervention on Participation Outcomes for HIV Positive Children on Haart and Living in Families with Low Socio-Economic Status

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research.

Please note the following:

a) Your research may not interfere with normal patient care
b) Hospital staff may not be asked to assist with the research.
c) No hospital consumables and stationary may be used.
d) **No patient folders may be removed from the premises or be inaccessible.**
e) Please introduce yourself to the person in charge of an area before commencing.
f) Please provide the research assistant/field worker with a copy of this letter as verification of approval.
g) Confidentiality must be maintained at all times.

I would like to wish you every success with the project.

Yours sincerely

DR BHAVNA PATEL
CHIEF EXECUTIVE OFFICER
Date: 14th January 2014

C.C. Mr Lionel Naidoo
Dr Janine Hendricks
Mrs Rogini Pillay

G46 Management Suite, Old Main Building,
Observatory 7925

Private Bag X,
Observatory, 7935

Tel: +27 21 404 6288 fax: +27 21 404 6125

www.capegateway.go.v.za

9.4.3 Letter for permission to conduct pilot study at Beautiful Gate, Lower Crossroads.

Faculty of Health Sciences
School of Health and Rehabilitation Sciences
Divisions of Occupational Therapy
F45 Old Main Building, Groote Schuur Hospital,
Observatory 7925
Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323
Internet: www.uct.ac.za

To Vaughan Stannard

This is a formal request for permission to conduct a pilot study at Beautiful Gate on a population comprised of HIV positive caregivers whose children attend the paediatric out-patients clinic at Crossroads Clinic.

The proposed study aims to investigate effects of play-informed caregiver-implemented home-based intervention (PICIHBI) on caregivers' level of CSE to promote learning, development and play in their HIV positive children (Aged 6 months to 8 years old) on Highly Active Anti-retroviral Treatment (HAART). There are well-established negative long-term consequences for learning and development for children affected with Acquired Immune Deficiency Syndrome (AIDS). While HAART has proven to be effective in prolonging life expectancy in children living with HIV/AIDS, access to comprehensive health care is critical for these children to continue enjoying quality of life. Caregivers of HIV+ children in South Africa often face contextual challenges that often limit their ability to support their children's optimal participation in learning, development, self-care and play. Consequently, the potential of these children to meet their participation needs as adolescents and adults is compromised.

There are limited studies detailing what may be appropriate and possibly effective responses to support caregivers with children infected with HIV, especially those on ART or HAART. Possible positive impact on supporting caregivers to promote learning, development, self-care and play for HIV infected children through PICIHBI may hold important promise for early childhood development and family inclusion in the country. A description of appropriate PICIHBI for families with low SES will inform relevant occupational therapy in South Africa. Efficacy in promoting children's meaningful and productive participation in life will be affirming for both caregivers and therapists.

As part of the research, an adapted version of the Parenting Self-Efficacy Measuring Instrument (P-SEMI) will be used to collect data at baseline, and twice at six monthly intervals. A pilot study is

necessary to establish content validity and administrative processes. 13 (10% of the main study sample) caregivers will be recruited from the caregivers with children that are currently being seen by the research for occupational therapy at Beautiful Gate. Data obtained from the assessment will inform ongoing intervention.

The study will adhere strictly to ethical principles as outlined in the Declaration of Helsinki (Seoul version, 2008). Ethics approval has been obtained from the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town (HREC Reference number 560/2013).

Caregiver informed consent will be sought before participation in the study resumes. There will be no coercion of any form in order gain participation from the study population and each caregiver-child dyad may withdraw from the study at any point in time, free of prejudice should they so wish. All personal information will be kept strictly confidential.

Please forward any question or concern you may have regarding this research to contact details furnished below.

Principal Investigator:

Ms Jessica Ferguson

email: ferguson.jes@gmail.com

cell: 076 235 6186

Chairperson of the UCT faculty of Health Sciences Human Research Ethics Committee:

Professor Marc Blockman

021- 406 6496

9.5 Appendix E: Information letters and consent forms

9.5.1 Information letter given to caregivers (English version)

Faculty of Health Sciences
School of Health and Rehabilitation Sciences
Divisions of Occupational Therapy
F45 Old Main Building, Groote Schuur Hospital,
Observatory 7925
Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323
Internet: www.uct.ac.za

Information letter to caregivers for participation in main research study

Dear parent/caregiver

Thank you for taking the time to read this information letter. My name is ..... and I am an occupational therapist (OT) busy doing research with other researchers.
We have found that many of our children attending our ARV clinics are developing and learning slowly and/or struggling at school. We have also found that our caregivers are struggling to meet the needs of their children in this specific area, of development and learning. Therefore, we are researching what are effective ways to improve development, play and learning for children living with HIV.

We are researching two different types of therapy. A computer program will randomly allocate all participants to only one of the two therapies so unfortunately you will not be able to choose which therapy you will receive.
One therapy involves individual therapy where your child would be seen by an occupational therapist for an hour, working on your child's specific needs. The other therapy involves 1,5 hour group sessions for caregivers and their children facilitated by an occupational therapist. These groups will assist caregivers to know how to stimulate their children at home. Both of these therapies are beneficial and will take place once a month at Groote Schuur with 10 sessions in total. Therefore, a monthly commitment will be required from you and your child to be able to attend most of the sessions.
To be able to see whether our therapy is effective we will need to assess the children and require you to fill in some forms. We need to assess the children before, during and after the therapy to record progress. Assessments will be approximately 2,5 hours and needs to be completed at 5 to 6 month intervals. For the assessments your child will be required to complete certain activities for example, building blocks, running or drawing. Your child will also be video recorded on how they naturally play in the Groote Schuur playroom. The researchers will be the only ones who will look at this video and then the video will be destroyed afterwards. You will also be required to fill in forms regarding general details about your family and how you feel about parenting. Your assessments and details will be kept strictly confidential.

At some point during the study, you will be provided with a 'GO box' (a take home toolkit) in which various materials such as balls, crayons, and toys will be provided for you to use with your child at home. Assessments and therapy will be carried out at Groote Schuur Hospital, at the pediatric out-patient clinic where you bring your child for follow-up treatment. The researchers will find out from you about suitable time convenient for you. You will be provided with R20 to help cover the cost of using public transport. You will receive this on the day of each visit.

You are under no pressure to participate in this study and you have the right to withdraw at any point without providing an explanation. There will be no penalty involved should you wish to withdraw. The researchers or the hospital cannot use your decision to refuse participation or withdraw against you in any way.

There are no risks in taking part in the study and there will not be any reward. Findings from the study will be analyzed by the research team and used for presentations, reports and research publications. Your identity will not be revealed when the results are reported for research.

Thank you for considering this request. Please find the consent form attached for you to complete. Ethics approval has been obtained from the Faculty of Health Sciences Human Research Ethics Committee of the University of Cape Town (HREC Reference number 560/2013).

Please forward any question or concern you may have regarding this research to the contact details furnished below.

Researchers' details:

Robyn Meissner (robyn.jess@gmail.com)

Jessica Ferguson (ferguson.jes@gmail.com)

Caraleigh Otto (caraleigh@nthandohome.co.za)

Anande Uys (anandeuys@gmail.com)

Cell: 0737150749

Principal Investigator:

A/Prof Professor Elelwani Ramugondo

Elelwani.Ramugondo@uct.ac.za

021- 406 6048

Chairperson of the UCT faculty of Health Sciences Human Research Ethics Committee:

Professor Marc Blockman

021- 406 6496

9.5.2 Caregiver consent Form

Faculty of Health Sciences
School of Health and Rehabilitation Sciences
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Observatory 7925
Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323
Internet: www.uct.ac.za

Consent form to participate in study titled: The effects of play-informed care-giver implemented home-based intervention on participation outcomes for HIV positive children on ART and living in families with low socio-economic status.

I, …… (caregiver's name) have received the information sheet from …… (researcher's name) about the research study.

The following has been explained to me:

☐ The purpose of the research study

☐ The two types of intervention: Group and individual therapy

☐ Monthly commitment for intervention

☐ R20 to assist with transport

☐ Assessment to record progress before, during and after intervention

☐ Video assessment

☐ Box of toys received at some time during the next 12 to 14 months

☐ Confidentiality

☐ No pressure or obligation to be part of the study

☐ I can withdraw at any stage without negative consequences

I understand what is required of me and my child to participate in the study. All my questions have been answered. I do not feel that my child or I are being forced to partake in this study. I choose to participate of my own free will. I am aware that I can withdraw from the study at any time should I wish to do so. I have been assured that if I refuse to participate in the study or choose to withdraw at a later stage there will be no consequences for me or my child.

Tick your chosen response:

☐ I do consent to both our participation in the study (you agree).

☐ I do NOT consent to both our participation in the study (you disagree).

Signed:…… Date: ……

Caregiver Full Name:……..

Place:…….

Researcher:……..……Signed:……

9.6.1 Child assent (English version)

Faculty of Health Sciences
School of Health and Rehabilitation Sciences
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Assent forms for child participants to participate in the main research study

Please circle the first face if you would like to be part of this study, or circle the second face if you would not like to be part of this study.

I am  happy to be part of the study

I am  unhappy to be part of the study

Signed:

Parent / Guardian Date and place

Researcher Date and place

Witness Date and place

9.7 Appendix F: Demographic questionnaire

Demographics Form

to be filled in by primary caregiver

Administrated by:

Participant number/code: _____

Grey sections are to be filled in by researchers only

CAREGIVER'S DETAILS

1. How much time during the week are you with your child? Please tick only ONE answer.

Lingaphi ixesha olichithayo nomtwana wakho?

☐ Less than 7 hours per week
☐ 8 to 20 hours per week
☐ more than 20 hours per week 1. _____

2. What is your home language?

Uthetha oliphi ulwimi?

☐ English
☐ Afrikaans
☐ isiXhosa
☐ isiZulu
☐ Shona
☐ seSotho
☐ Other (specify) _____ 2. _____

3. Please indicate which of the 3 following languages is most spoken in your home. Tick ONE answer.

Bonisa loliphi ulwimi kula mathathu enilisebenzisa endlini.

☐ English
☐ Afrikaans
☐ isiXhosa

3. _____

4. What language do you prefer to read? Tick One

Ufuna unfunda ngoluphi ulwimi.

☐ I cannot read
☐ English
☐ Afrikaans
☐ Xhosa

☐ I cannot read any of these specific languages 4. _____

5. What is YOUR (caregiver) age?
***Mingaphi iminyata yakho?* _____** 5. _____

6. What is YOUR (caregiver) gender? (*Please tick your answer)*
Sithini isini sakho?

☐ Male
☐ Female 6. _____

7. What is YOUR (caregiver) highest level of education COMPLETED?
Loluphi ubanga oluphezulu elwenzileyo?

☐ None
☐ Grade 1
☐ Grade 2
☐ Grade 3
☐ Grade 4
☐ Grade 5
☐ Grade 6
☐ Grade 7
☐ Grade 8
☐ Grade 9
☐ Grade 10
☐ Grade 11
☐ Grade 12 (Matric)
☐ 1 year post school
☐ 2 years post school
☐ 3 years post school
☐ 4 or more years post school 7. _____

8. Are you the biological parent of the child?
Ungumzali womtwana?

☐ Yes
☐ No 8. _____

9. If you answered 'no' to the above question, what is your relationship with the child?
Ukuba awunguye uyintoni emntwaneni?
☐ Grandparent
☐ Aunt / uncle
☐ Sister / brother
☐ Foster parent
☐ Other. Please specify _____ 9. _____

10. How many children under the age of 18 do you take care of, in total (including child attending clinic)?

Bangaphi abantwana obanakekewayo abangaphantsi kweminyaka elishumi elinesibhozo?

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ more than 7

10. _____

11. How old are the other children in the house? Fill in the children's ages in the gaps below.

Ungowesingaphi umntwana kubantwana bakho enduni?

Age of child 1: _____; age of child 2: _____; age of child 3: _____; age of child 4 _____; age of child 5: _____; age of child 6: _____; age of child 7: _____

11. _____

12. How many other adults over the age of 18 do you live with at home?

Bangaphi abanye abantu abadala abangaphezulu kweminyaka elishumi elinesi bhozo?

- ☐ 0, I do not live with any other adults
- ☐ 1 other
- ☐ 2 others
- ☐ 3 others
- ☐ 4 others
- ☐ 5 others
- ☐ 6 others
- ☐ 7 others
- ☐ more than 7 others: Specify ____ others.

12. _____

13. What is the total amount of money that you and your family (who you live with) live off every month? This INCLUDES salaries, grants and all other sources of income.

Yimalini imali olubanayo usapho lwakho ngempela nyanga?

- ☐ No income
- ☐ R1 - R400
- ☐ R401 - R800
- ☐ R801 - R1 600
- ☐ R1 601 - R3 200
- ☐ R3 201 - R6 400
- ☐ R6 401 - R12 800
- ☐ R12 801 - R25 600

☐ R25 601 - R51 200
☐ R51 201 - R102 400
☐ R102 401 or more 13. _____

14. What is YOUR (caregiver) level of employment?
Lithini izinga lomsebenzi/lengzesho?

☐ Unemployed: ☐ Looking for work ☐ Stay at home mom/parent ☐ Retired
☐ Kidzpositive Beadwork project
☐ Self-employed
☐ Part-time employment
☐ Full-time employment
☐ Seasonal/occasional employment 14. _____

CHILD'S DETAILS

15. What is your child's date of birth?
Uzelwe nini umntwana wakho? _____ 15. _____

How many weeks were you/the biological mother pregnant when the child was born?
Ubuneveki ezingaphi ngoki ubunkhule lwe uzaku beleka?

☐ Under 29 weeks. The child was born very early – more than 3 months early (very premature).
☐ 29 to 36 weeks. The child was born early (premature)
☐ 37 weeks or more. The child was born at full term.
☐ I do not know 16. _____

16. Were there any problems during birth?
Zibekhona ingxaki xa ubeleka?

☐ Yes. Please specify _____
_____
☐ No
☐ I do not know 17. _____

17. Are there any other confirmed medical diagnoses (other than HIV+)?
Zibekhona ezingxelo ezibonwe kuwe ngugqirha ngaphiondle ko gawulayo?

☐ Yes. Please specify
_____
☐ No
☐ I do not know 18. _____

18. Where is your child usually during the day in the week? Tick ONLY ONE.

Ubaphi umntwana wakho emini phakathi, evekini?

☐ My child attends crèche/play school
☐ My child attends formal school
☐ My child stays with me during the day
☐ My child goes to another friend/family member/day mother during the day 19. _____

19. What is the name of your child's school?
Ngubaniigama lomntwana wakho esikolweni?

Please specify _____
☐ My child does not go to school. 20. _____

20. If your child is in school, what grade is he/she in?
Ukuba umntwana wakho useskolweni/wenza eliphi ibanga?

☐ Crèche
☐ Grade R
☐ Grade 1
☐ Grade 2
☐ Grade 3
☐ My child is not in school 21. _____

21. If your child is in school, is it a mainstream school or special school?
Ingaba umntwana wakho usesikolweni? Sisikolo somntu wonke okanye sesemeko emalunga nomntwana?

☐ Mainstream (normal) school
☐ Special school
☐ My child is not in school 22. _____

22. If your child is in school, has he or she failed any grades?
Mntwana wakho ukhe waliphinda ibanga?

☐ Yes. Specify grade _____
☐ No
☐ My child is not in school 23. _____

23. If your child is attending school, what is the main language medium of the school that is taught to your child?
Ukube umntwana wakho uyafunda loluphi ilwini lakhe lokuqala?

☐ English
☐ Afrikaans
☐ Xhosa
☐ Other. Please specify _____

☐ My child is not in school 24. _____

24. How long has your child been on HAART?
Unexesha elingakanani umntwana wakho efumana unyango?

☐ Less than 2 months
☐ 2 - 6 months
☐ 7 - 11 months
☐ 1 year
☐ 2 years
☐ 3 years
☐ 4 years
☐ 5 years
☐ 6 years
☐ 7 years
☐ 8 years 25. _____

25. How do you feel about your child's learning, development and play skills? Please tick <u>1 ONLY</u>
Uva njani ngezifundo zomntwana wakho, kwizakhono zophuhliso?

☐ I am very concerned that he/she is developing very slowly and is far behind other children of the same age
☐ I feel that he/she is developing a little slower than other children of the same age
☐ I feel he/she is developing the same as other children his/her age
☐ I feel that he/she is developing a little better than other children of the same age
☐ I feel that he/she is developing very well and is far above the average compared to other children of the same age 26. _____

26. Is your child <u>currently</u> attending any of the following services? Tick ALL that apply
Ingaba umntwana wakho uyazifunda ezizifundo zilandelayo?

☐ Speech therapy
☐ Physiotherapy
☐ Occupational therapy (OUTSIDE OF GSH)
☐ Remedial teaching
☐ Psychologist
☐ Audiology
☐ Dietician
☐ Other. Please specify _____
☐ None, my child is not attending any other support services outside of GSH 27. _____

27. Has your child previously attended any of the following services? Tick ALL that apply
Ingaba umntwana wakho ukhe wahlangana nenye yesinkqubo?

☐ Speech therapy
☐ Physiotherapy
☐ Occupational therapy (OUTSIDE OF GSH)
☐ Remedial teaching
☐ Psychologist
☐ Audiology
☐ Dietician
☐ Other. Please specify _____ 28. _____
☐ None, my child is not attending any other support services outside of GSH

28. Has your child ever had their hearing tested? (at school or at hospital/clinic)?
Umntwana wakho ukhe waxilongelwa ndlebe esikolweni okanye esibhedlela/ekliniki?

☐ Yes: result: ☐ normal/good hearing; ☐ poor hearing
☐ No
☐ I do not know

29. Has your child ever had their vision tested? (at school or at hospital/clinic)?
Umntwana wakho uke waxilo ngelwa amehlo? Esikolweni okanye esibhedlela/ekliniki?

☐ Yes: result: ☐ normal/good vision; ☐ poor vision
☐ No
☐ I do not know

30. Can you specify any concerns that you might have about your child's development (if any).
Ungasichazela ngendlela ovangayo ngokukhula komntwana wakho.

_____
_____
_____
_____

31. Who is the MAIN person who plays with the child? Tick only ONE
Ngubani oyena mntu udlala nomntwana?

☐ The child mainly plays by himself/herself

☐ You, the caregiver

☐ Another adult (over 18 years)

☐ A younger child in your house

☐ An older child in your house (that is younger than 18 years)

☐ Another child outside the house eg (neighbour or friend)

32. What are 3 of your child's favourite toys that s/he plays frequently with?
Zintoni ezintathu zokudlala ezinthandwa ngumntwana wakho?

1. _____
2. _____
3. _____

33. Do you have a television inside your home?
Unaye umabona-kude?

☐ Yes

☐ No, we do not own a television.

34. Is the television on every day?
Umabona-kude udlala yonke imihla?

☐ Yes
☐ No
☐ We do not own a television.

35. Does your child watch television every day?
Umntwana wakho ubukela yonke imihla umabonakude?

☐ Yes

☐ No
☐ We do not own a television.

36. How many hours a day does your child watch television? Tick only ONE.
Uwubukela iyure ezingaphi umntwana wakho umabonakude ngosuku?

☐ Less than 1 hour

☐ 1 hour

☐ 2 hours

☐ 3 hours

☐ 4 hours

☐ 5 hours or more

☐ We do not own a television.

37. Does your child play in the same room/area as the television? Tick only ONE.
Ingaba umntwana wakho udlala kweligumbi linye linomabonakude okanye kwelinye?

☐ Yes
☐ No
☐ No, my child is not allowed to play inside.
☐ We do not own a television

38. Where inside the house does your child play (if they are allowed to play inside)?
Udlala phi imntwana wakho endlwini?

_____
_____

---------- Thank you for taking the time to complete this form ----------

TO BE FILLED IN BY RESEARCHER

Separate page of info to get from file or Road to Health card

Participant Code: _____

a) Primary Dr: _____

b) Primary Counsellor: _____

Birth History

c) Gestation: _____

d) Birth weight: _____

e) Apgar 1min: 5min: ☐ not recorded:

f) Birth delivery: _____

g) Birth complications: _____

Medical History

h) Date Started HAART _____

i) Date Enrolled at G26 clinic _____

j) Defaults History _____

k) Line of Treatment _____

l) TB History _____

m) Other Diagnoses _____

Complimentary services

n) Other services attended in past. Eg dietician (Specify when, how often, GSH or service site etc)

Services currently attending (Specify when, how often, GSH or service site etc)

_____

_____

_____

_____

_____

9.8 Appendix G: Combined self-efficacy measures administered

Section A: P-SEMI; Section B: PSOC; Section C: GSE

PSEMI - Parenting Self-Efficacy Measuring Instrument

Date: _____ _____ **Assessment:** ☐ Baseline ☐ Mid ☐ Post
Assessor's Initials: _____
Family Participant number: _____ **Caregiver Participant Number: _____**

☐ Self administered; ☐ Self-administered with questions asked to translator/researcher as needed
☐ Done with Researcher; ☐ Done with Translator.

SECTION A

Instructions: *This questionnaire consists of 43 statements about parenting. Please read each statement and circle the number that best describes you. Please describe yourself* ***honestly*** *as you really are now, not as you would like to be in the future. There is no "right" or "wrong" answer. Please* ***answer all questions****, even if it does not apply to you very well. Your answers will be kept strictly confidential.*

No.	Statement	Always/ Yonke imhla	Almost Always/ pantse yonke imihla	Often/ kancinane	Sometimes/ ngamaxesha athile	Seldom	Never/ Soze	For official use only
1	I can discipline my child, no matter how I am feeling. *Ndiyakwazi ukumqeqesha umntwana wam, noba ndikwesiphi isimo.*	1	2	3	4	5	6	
2	I can maintain the established routine (e.g. bath time, getting dressed etc) when my child protests. *Ndinga zamalula ukumenza umtana ayazinto ayenzayo qho ngemhla noba akacacelanga kwenzanto/akafuni e.g. ukuhlamba, ukuzi nxibisa, azityele ukutya.*	1	2	3	4	5	6	
3	I can get my child to participate in play activities even when s/he doesn't want to. *Ndiyakwazi ukwenza umntwana wam ukuba athathe inxaxheba kwezemidlalo, nokuba akafuni.*	1	2	3	4	5	6	
4	I can create daily opportunities for conversation/communication with my child. *Ndiyakwazi ukuzama ukufumana ithuba lokuba ndibenencoko nomntwana wam imihla ynoke.*	1	2	3	4	5	6	

5	I can discipline my child as well as any other parent can. *Ndiyakwazi ukuqeqesha umntwana wam ngalendlela abanye abazali baqeqesga ngayo.*	1	2	3	4	5	6	
6	I can make time to tell my child I love him/her no matter how I am feeling. *Ndiyalenza ixesha lokuba ndixelele umntwana wam ukuba ndiyamthanda ngalo lonke ixesha, nokuba ndikwesiphi isimo.*	1	2	3	4	5	6	
7	I can easily spend time playing with my child. *Ndiyakwazi uchitha ixesha ndidlala nomntwana wam.*	1	2	3	4	5	6	
8	I can show my child love and be affectionate, as well as any other parent can. *Ndiyakwazi umbonisa umntwana wam uthando kwaye nobunjani bobomi, njengaye wonke umzali esenza emntwaneni wakhe.*	1	2	3	4	5	6	
9	I can use daily routines and activities to teach my child responsibilities. *Ndiyakwazi ukusebenzisa endlela enye oko yokwenza iizinto ekufundiseni umntwana wam uxanduva.*	1	2	3	4	5	6	
10	I can help my child to successfully complete daily routines and activities. *Ndiyakwazi uncedisa umntwanawam ukuba agqibe izinto zakhe azenzayo mihla yonke.*	1	2	3	4	5	6	
11	I can communicate easily with my child. *Ndiyakwazi ukuthethusana nomntwana wam lula.*	1	2	3	4	5	6	
12	I can find time to assist my child to complete daily routines when I am having a bad day. *Ndiyakwazi ukufumana ixesha lokancedisa umntwana wam noba ndibenemini engantlanga.*	1	2	3	4	5	6	
13	I can get my child to follow a routine (e.g. Bedtime) as well as any other parent can. *Ndiyakwazi ukufundisa umntwana wam ukuba alandele umgaqo (umzekelo alale ngexesha elinye mihla yonke) njengalendlela wonke umzali enza ngayo.*	1	2	3	4	5	6	
14	I can teach my child the necessary things s/he needs to know to become successful and independent one day. *Ndiyakwazi ukufundisa umntwana wam isinto eziyimfuneko ukuba azizi ebomini ukuze aphumelele kwaye azimele.*	1	2	3	4	5	6	
15	I can listen to advice from other people about how I should discipline my child. *Ndiyakwazi ukumamela ingcebiso ezisuka kwabanye abantu ukuba ndimqeqesha njani umntwana wam.*	1	2	3	4	5	6	
16	I can set realistic limits and boundaries for my child. *Ndiyakwazi umohlulela umntwana wam*	1	2	3	4	5	6	

	phakwathi kobomi bamanyani esibuphilayo kwakunye nezinto nje zalapha.							
17	I can understand my child's personality and moods. *Ndiyazazi kwaye ndiyabuvisisa ubume/ubunjani bomntwana wam nomdla wakhe.*	1	2	3	4	5	6	
18	I can let my child know I still love him/her, after I have disciplined him/her for misbehaving. *Ndiyakwazi ukumazisa umntwana wam ukuba ndiyamthanda noba bendigqiba mbetha/ngxolisa xa ebemoshile.*	1	2	3	4	5	6	
19	I can make time in my schedule to teach my child new things s/he needs to know. *Ndiyalenza ixesha lokuba ndilichithe nomntwana wam ndimfundise izinto ezintsha ekufuneke ezazile.*	1	2	3	4	5	6	
20	I can spend time just talking with my child when I myself am feeling stressed. *Ndiyakwazi ukufumana ixesha lokukhetha nomntwana wam xa ndingaphathekanga kakuhle.*	1	2	3	4	5	6	
21	I can regularly make time to spend with my child. *Nyiyakwazi uchitha ixesha elininzi ndihleli nje nomntwana wam.*	1	2	3	4	5	6	
22	I can teach my child as well as any other person I know. *Ndiyakwazi ukumfandisa umntwana wam kwakunye nomnye umntu endimaziyo.*	1	2	3	4	5	6	
23	I can make time to talk with my child even though I have other important things to do. *Ndiyakwazi uthetha nomntwana wam nokuba kukho ezinye izinto ezibalulekileyo ekufuneka ndizenzile.*	1	2	3	4	5	6	
24	I can allow my child the freedom to make appropriate decisions on their own. *Ndiyakwazi ukuvumeka umntwana wam ukuba enze iizigqhibo ezimele kwaye enenkululeko yokwenza uko.*	1	2	3	4	5	6	
25	I can understand what my child is saying as well as any other parent would. *Ndiya mvisisisa umntwana wam njenga banye abazali besenza.*	1	2	3	4	5	6	
26	I can think of activities to do with my child that will encourage him/her to learn. *Ndiyakwazi ukucinga imisebenzi esinothi siyidlale mna nomntwana wam kwaye akwazi ukufunda kuyo lomidlalo.*	1	2	3	4	5	6	
27	I can encourage my child to learn new things as easily as other parents can. *Ndiyakwazi ukucebisa ndiphinde ndimqondise ukuba umntwana wam makafunde izinto entsha, njengabanye abazali*	1	2	3	4	5	6	

	besenza.							
28	I can figure out which activities my child enjoys doing. *Ndiyakwazi ukufumanisa ukuba ngomphi umdlalo awuthandayo.*	1	2	3	4	5	6	
29	I can make sure that my child will participate and learn from opportunities in his/her environment. *Ndiyakwazi ukuqinisekisa ukuba umntwana wam uthatha inxaxheba kwaye aphinde afunde kumathuba awafumana ekuhlaleni.*	1	2	3	4	5	6	
30	I can enjoy talking with my child as much as any parent would. *Ndiyakwazi ukonwaba ukuncokola nomntwana wam njenga banye abazali besenza.*	1	2	3	4	5	6	
31	I can discipline my child if s/he misbehaves when we are visiting close friends. *Ndiyakwazi ukuqeqesha umntwana wam xa engaziphatanga kakuhle nokuba sindwendwele isihlobo sethu sokwenene.*	1	2	3	4	5	6	
32	I can stay motivated to continue an activity with my child when it appears as if s/he is not learning as much as I have hoped s/he would. *Ndiyakwazi uhlala ndisemdleni owodlala imidlalo nomntwana wam nokuba akabonakalisi enomdla wodlala nowokufunda.*	1	2	3	4	5	6	
33	I can enjoy playing with my child as much as any other parent can. *Ndiyakonwabela ukudlala nomntwana wam njenga banye abazali besenza.*	1	2	3	4	5	6	
34	I can listen to other people's advice about daily routines for my child. *Ndiyakwazi ukumamela ingcebiso ezisuka kwabanye abantu ukuba ndimqeqeshe njani umntwana wam.*	1	2	3	4	5	6	
35	I can adapt activities that I can see other parents and children enjoying so that my child and I can enjoy them too. *Ndiyakwazi uthatha imidlalo ngabanye abazali nabantwana babo ebonwabisayo, nam ndiye ndiyithathe ngaba ndifuna nam nomtwana wam isonwabise.*	1	2	3	4	5	6	
36	I can discipline my child if they misbehave when we are in a public place i.e. shopping centre. *Ndiyakwazi ukuqeqesha umntwana wam xa engaziphathanga kakuhle esidlangalaleni (umzekelo xa sisedolophini).*	1	2	3	4	5	6	
37	I can create a home environment that promotes security and trust. *Ndiyakwazi ukwakha ikhaya elizokukhulisa.*	1	2	3	4	5	6	
38	I can demonstrate warmth and acceptance to my child as well as any other parents can. *Ndiyakwazi*	1	2	3	4	5	6	

	ukubonisa ufundumalo kwakunye nokwamkeleka kumntwana wam njengabanye abazali.							
39	I can learn from watching how other parents discipline their children. *Ndiyakwazi ukufunda ngokubukela indlela abanye abazali abaqeqesha ngayo abantwana babo.*	1	2	3	4	5	6	
40	I can discipline my child in ways which are consistent. *Ndingakwazi ukuqeqesha umntwana wam ngendlela engatshintshiyo.*	1	2	3	4	5	6	
41	I can think of fun activities for my child to do which s/he will not find boring. *Ndiyakwazi ukucinga indlela yokudlala ezi umntwana wam angazifumana zidika.*	1	2	3	4	5	6	
42	I can use the opportunities that come up in daily activities to show my child how much I care for him/her. *Ndiyakwazi ukusebenzisa amathuba azivelelayo kwimidlalo esiyenzayo ngosuku ukubonisa umntwana wam ndimkhathalele.*	1	2	3	4	5	6	
43	I can understand the importance of establishing and maintaining a set routine for my child. *Ndiyakuvisisa ukubaluleka koku khulisa imigaqo kumntwana wam (wemidla yonke).*	1	2	3	4	5	6	

---------- **End of Section A** ----------

SECTION B

Instructions: *This questionnaire consists of 17 statements about parenting. Please read each statement and circle the number that best describes how you feel. Please* ***answer all questions****.*

No.	Statement/Incukacha	Strongly Agree/ Ndyiavuma ngamandla	Agree/ Ndiyavuma	Slightly Agree/ Ndiyavuma kancinci	Slightly Disagree/ Andiqinisekanga	Disagree/ andivumi	Strongly Disagree/ Andivumi ngamandla	For official use only
1	I understand how my actions affect my child which helps me to solve problems of taking care of my child. *Iingxaki yokuthathalela umntwana kulula ukuzilungisa xa usazi ukuba indlela awenza ngayo izakumphatha njani umntwana wakho.*	1	2	3	4	5	6	
2	I meet my own personal goals in caring for my child. *Ndiyadibana nomqeqeshi endinaye yokhathalela umntwana wam.*	1	2	3	4	5	6	
3	I would be a good example to a new parent in order to learn what s/he would need to know to be a good parent. *Ndizokwenza umzekeliso obalaseleyo kumzali omtsha, apho azofundisa khona umntwana wakhe kwaye abengumzali obalaseleyo emntwaneni wakhe.*	1	2	3	4	5	6	
4	Being a parent is manageable, and any problems are easily solved. *Xa ungumzali kuyaphatheka, kwaye zonke iingxaki zilungiseka lula.*	1	2	3	4	5	6	
5	If anyone can find the answer to what is troubling my child, I am the one. *Ukuba kukho bani ongafumana impendulo yento esokolisa umntwana wam, ndim ndodwa.*	1	2	3	4	5	6	
6	A difficult problem about being a parent is not knowing whether you're doing a good job or a bad one. *Eyona ngxaki inzima xa ungumzali kukuba ungayazi nokuba wenza umsebenzi omhle okanye ombi na.*	1	2	3	4	5	6	
7	Considering how long I have been a parent, I feel thoroughly familiar with the role. *Ndicingisisa ukuba mingaphi iminyaka ndingu mzali kodwa ndiziva ndibuqhela koluxanduva.*	1	2	3	4	5	6	
8	I honestly believe I have all the skills necessary to be a good parent to my child. *Ndiyakholelwa ukuba*	1	2	3	4	5	6	

	ndinazo zonke izakhono ezifunekayo zokuba ndibe ngumzali olungileyo.							
9	Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age. *Noxa kungumvuzo ukuba ngumzali, ndixakiwe ngoba kuba umntwana wam ekule minyaka akuyo ngoku.*	1	2	3	4	5	6	
10	I do not know why it is but sometimes when I'm supposed to be in control, I feel more like the one being manipulated. *Andiyazi kutheni inje, kodwa ngamaxesha athile xa kufuneka ndiphathe, ndiziva njengomnye ocalulwayo.*	1	2	3	4	5	6	
11	My mother was better prepared to be a good mother than I am. *Umama wam wayebhetele ngokulungela ukuba ngumzali olungileyo ukodlula mna.*	1	2	3	4	5	6	
12	Sometimes I feel like I'm not making any progress with my child. *Ngamanye amaxesha ndiziva ngathi akukho kwanto endiyifumana igqityiwe.*	1	2	3	4	5	6	
13	I go to bed the same way I wake up - feeling that I have not accomplished a whole lot during the day. *Ndilala ngexesha elinye mihla yonke kwaye ndivuke ndiziva ngathi andiphumelelanga ukwenza into ebekumele ndiyenze.*	1	2	3	4	5	6	
14	My talents and interests are in other areas, not in being a parent. *Iziphiwo zam kunye nezinto endinomdla kuzo zikwezinye indawo, hayo ekabeni ngumzali.*	1	2	3	4	5	6	
15	If being a parent of an infant were only more interesting I would be motivated to do a better job as a parent. *Ukube ngumzali womntwana omncinci kuyonwabisa, ndinga nomdla ukwenza umsebenzi ongcono ukuba ngumzali.*	1	2	3	4	5	6	
16	Being a parent makes me tense and anxious. *Ukuba ngumzali ndingakhululeki kwaye ndisoyika.*	1	2	3	4	5	6	
17	Being a good parent is a reward in itself. *Ukuba ngumzali obalaseleyo kuliwonga kubazali.*	1	2	3	4	5	6	

---------- **End of Section B** ----------

SECTION C

Instructions: *This questionnaire consists of 15* ***statements about <u>general coping</u> in life and does not necessarily refer to parenting****. Please indicate your own feelings about each statement below by circling the number that best describes how you feel. There is no "right or "wrong" answer. Please answer every question, even if it does not apply to you very well. Your answers will be kept strictly confidential.*

No.	Statement/Incukacha	Strongly Agree/ Ndyiavuma ngamandla	Agree/ Ndiyavuma	Slightly Agree/ Ndiyavuma kancinci	Slightly Disagree/ Andiqinisekanga	Disagree/ andivumi	Strongly Disagree/ Andivumi ngamandla	For official use only
1	I can always manage to solve difficult problems if I try hard enough. *Ndingazama oko ukulungisa ingxaki ezcinzima ukuba ndizama nzima ngokwanelayo .*	1	2	3	4	5	6	
2	If someone opposes me, I can find a way to get what I want. *Ukuba omnye umntu uphikisana nam, ndingafuna ezinye indlela zokuba ndifumane into endiyifunayo.*	1	2	3	4	5	6	
3	It is easy for me to stick to my aims and accomplish my goals. *Kulula kum ukuzinza endizifunayo kwaye ndiyafikelela kuzo.*	1	2	3	4	5	6	
4	I am confident that I could deal efficiently with unexpected events. *Ndizithembile ukuba ndingakwazi ukumelanga nezinto ezingaqhelekanga.*	1	2	3	4	5	6	
5	Thanks to my resourcefulness, I know how to handle unforeseen situations. *Ndiyabulela kumncedisi, ndiyakwazi ukumaneja isimo esingesihlanga.*	1	2	3	4	5	6	
6	I can solve most problems, if I put in the necessary effort. *Ndingazilungisa ingxaki ecininzi ukuba ndithatha inxaxheba efunekayo.*	1	2	3	4	5	6	
7	I can remain calm when facing difficulties because I can rely on my coping abilities. *Ndingakwazi ukuhlala ndizolile nokube isimo sinzima kanjani na.*	1	2	3	4	5	6	
8	When I am confronted with a problem, I can usually find several solutions. *Xa ndijongene nengxaki, ndifumana izisombululo kwangoko.*	1	2	3	4	5	6	
9	If I am in trouble, I can usually think of a solution. *Ukuba ndise ngxakini, ndivele ndicinge ngesisombululo.*	1	2	3	4	5	6	

10	I can usually handle whatever comes my way. *Ndiyakwazi ukujongana nayo noba yintoni esendleleni yam.*	1	2	3	4	5	6	
11	I am always courteous even to people who are disagreeable. *Ndasoloko ndithobekile kumntu wonke, nakwabo ndingavumelani nabo.*	1	2	3	4	5	6	
12	There have been occasions when I took advantage of someone. *Kukho amaxesha xa kwenzeka into abantu bathathe uncedo lomnye umntu.*	1	2	3	4	5	6	
13	I sometimes try to get even rather than forgive and forget. *Ngamanye amaxeshwa ndiyazama ukufunana endaweni yokuba ndixolele kwaye ndilibale.*	1	2	3	4	5	6	
14	I sometimes feel resentful when I don't get my way. *Ngamanye emaxesha ndiziva ndinga balule kanga xa ndisenza into ngendlela engekhoyo.*	1	2	3	4	5	6	
15	No matter who I'm talking to, I'm always a good listener. *Nokuba ndithetha nabani, ndisoloko ndimamele ngendlela elungileyo.*	1	2	3	4	5	6	

---------- **End of Section C** ----------

Thank you for completing the Questionnaire

Siyabulela ngoko phendula lemibuzo

9.9 Appendix H: Self-efficacy measuring instruments administration memo

The combined instruments should consist of 4 pages that are stapled together.

Check in which language the caregiver would like to complete the assessment. Make the availability of a translator option known.

Explaining assessment to caregiver

Verbatim example:

This questionnaire consists of 3 sections. The first two sections, section A and section B, asks questions about parenting and the third section asks questions about coping in general and is not specific to parenting (show sections in questionnaire). In section A, for each statement you need to rate how applicable it is to you on a scale from 1 to 6 or Always to Never (show caregiver on form). Therefore, for each statement ask yourself "is this true for me always/almost always/often/sometimes/seldom/never?" For example, the first statement you will see is "I can discipline my child, no matter how I am feeling" – you will think if that is true for you always, almost always, often, sometimes, seldom or never.

Explain:

- Answer ALL questions (ensure you have completed all 4 pages)
- Take your time. Please do not rush.
- There is no "right" or "wrong" answer.
- Answer according to how you are now and not how you would like to be in the future. Do not try answer according to what you think you want us to hear. Try your best to be honest.
- Remember your questionnaire is kept confidential among research team and you only have a code written on the questionnaire. And others will not be able to know it is your questionnaire (only the researchers will know the codes).

Encourage caregivers to ask questions if they are confused.

NB: Once the PSEMI is completed and handed back, **before the caregiver leaves** ensure that:

- **the participant number is written on the top**
- **all questions have been answered**

9.10 Appendix I: PICIHBI (or GO KIDZ) session structure and GO Box examples

Toddler group (Caregivers and children 6 months to 2 years)

Session	Session focus
1	Introduction to programme and gross motor skills
2	Play: preconstruction and discovery
3	Fine motor skills
4	Early literacy and language
5	Self-care and independence
6	Gross motor skills
7	Play: preconstruction and discovery
8	Fine motor skills
9	Early literacy and language
10	Self-care and closure of programme

GO Box items:

Pre-school group (Caregivers and children 3 to 5 years)

Session	Session focus
1	Introduction to programme and gross motor skills
2	Fine motor skills
3	Literacy and language
4	Position, body awareness and visual perception
5	Size and number
6	Gross motor skills
7	Fine motor skills
8	Literacy and language
9	Shape
10	Size and number and closure of programme

GO Box items:

Foundation phase group (caregivers and children 6 to 8 years)

Session	Session focus
1	Introduction to the programme and gross motor skills
2	Fine motor skills
3	Literacy: speaking and listening, basic concepts
4	Numeracy: Shapes
5	Numeracy: patterns
6	Literacy: letters and phonics
7	Numeracy: counting
8	Literacy: letters and phonics
9	Numeracy: calculations
10	Literacy: reading and expression

GO Box items:

9.11 Appendix J: Item-total correlations and Cronbach alpha reliability coefficients for P-SEMI and PSOC subscales and GSE scale.

P-SEMI Subscales (*n* = number of valid cases analysed)	Items in each subscale	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Cronbach alpha values
Establishing discipline strategies (*n* = 60)	1	0.49	0.69	0.73
	5	0.40	0.70	
	15	0.45	0.70	
	16	0.26	0.73	
	31	0.57	0.67	
	36	0.48	0.69	
	39	0.28	0.73	
	40	0.47	0.70	
Facilitating routines (*n* = 59)	2	0.41	0.56	0.62
	9	0.39	0.57	
	10	0.41	0.56	
	12	0.56	0.50	
	13	0.48	0.54	
	34	0.00	0.75	
	43	0.39	0.57	
Engaging in play (*n* = 56)	3	0.18	0.64	0.61
	7	0.57	0.49	
	26	0.21	0.61	
	28	0.60	0.49	
	33	0.22	0.60	
	35	0.20	0.63	
	41	0.46	0.52	
Promoting communication interaction (*n* = 56)	4	0.35	0.73	0.74
	11	0.57	0.70	
	20	0.44	0.71	
	21	0.31	0.74	
	23	0.57	0.68	
	25	0.56	0.68	
	30	0.51	0.69	
Showing affection and empathy (*n* = 57)	6	0.27	0.63	0.64
	8	0.23	0.64	
	17	0.28	0.63	
	18	0.25	0.63	

	37	0.39	0.60	
	38	0.54	0.53	
	42	0.53	0.55	
Providing appropriate activities for learning and development (*n* = 58)	14	0.48	0.64	0.69
	19	0.65	0.59	
	22	0.24	0.70	
	24	0.20	0.73	
	27	0.46	0.64	
	29	0.49	0.63	
	32	0.46	0.64	

PSOC Subscales (n = number of valid cases analysed)	Items in each subscale	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Cronbach alpha values
PSOC satisfaction subscale (*n* = 54)	6*	0.09	0.82	0.79
	9*	0.46	0.77	
	10*	0.50	0.77	
	12*	0.63	0.75	
	13*	0.69	0.74	
	14*	0.69	0.73	
	15*	0.60	0.75	
	16*	0.51	0.76	
	17	0.01	0.81	
PSOC efficacy subscale (*n* = 50)	1	0.28	0.48	0.52
	2	0.18	0.50	
	3	0.30	0.47	
	4	0.39	0.42	
	5	0.51	0.39	
	7	0.48	0.39	
	8	0.41	0.43	
	11	-0.21	0.71	

*reversed questions (these were transformed first for analysis so all items showing high and low).

GSE (*n* = number of valid cases analysed)	Items in scale	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted	Cronbach alpha values
GSE total scale	1	0.32	0.78	0.78
(*n* = 56)	2	0.27	0.79	
	3	0.44	0.77	
	4	0.58	0.75	
	5	0.60	0.75	
	6	0.09	0.80	
	7	0.58	0.75	
	8	0.61	0.75	
	9	0.59	0.75	
	10	0.51	0.76	

Word count

Total word count: 34667

Word count excluding reference list: 31194

Word count inclusive of appendices: 42320